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ABSTRACT

The bibliography contains approximately 180 references dated from 1976 through 1986 concerning community integration for persons with severe disabilities. Output of computer searches of bibliographic data bases was evaluated according to the degree to which each item reflected principles of community integration. Usually provided for each citation are title, author, publication date, source, cost, and a summary with critical comments. Citations are organized into the following categories and subcategories: perspectives on integrated community services; funding integrated community services; planning and coordinating a comprehensive community service system; services (community living, educational, vocational, respite and family support, case management, guardianship, early childhood); assuring quality services; programming (individual planning, serving people with challenging behaviors, serving people with physical disabilities, meeting people's medical needs in the community, skill development, staff training); achieving community acceptance; and parents, consumers, and advocates. Also included are title and author indexes to the citations. (DB)

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Center on Human Policy

ANNOTATED BIBLIOGRAPHY ON COMMUNITY INTEGRATION FOR PEOPLE WITH SEVERE DISABILITIES

EC 210 386

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Annotated Bibliography
on
Community Integration
for
People with Severe Disabilities

Edited by

James Knoll

Entries by James Knoll, Steven Taylor, Julie Racino
Amy Good, Rannveig Traustadottir, Stanford Searl,
Luanna Meyer, Alison Ford, Jan Nisbet and
Douglas Biklen.

1987

THE COMMUNITY INTEGRATION PROJECT

The Center on Human Policy
Division of Special Education and Rehabilitation
Syracuse University
724 Comstock Avenue
Syracuse, NY 13244-4230

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THE COMMUNITY INTEGRATION PROJECT

is designed to provide technical assistance and disseminate information about model programs and practices which serve persons with the most severe disabilities in integrated community settings.

Project Director: Steven Taylor
Project Officer: Naomi Karp
Contract Officer: Michael Caporaletti

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INTRODUCTION

The materials listed here are intended to provide policy makers, direct service providers, advocates, and parents with the best available resources on the provision of community-based services to those individuals who are usually classified as the "hardest to serve" or "most severely disabled." This includes individuals who are labeled as severely or profoundly mentally retarded, autistic, multiply disabled, medically fragile, or presenting serious behavior problems.

Selection Process

Materials were initially identified by computerized searches of the ERIC (Educational Resource Information Center), NIMH (National Institute for Mental Health), and MEDLARS (Medical Literature Analysis and Retrieval System) databases and a review of a) the resources of the library of the Association for Persons with Severe Handicaps, b) the bibliographies published by the American Association on Mental Deficiency, c) the contents of the major journals in the field over the last ten years, d) the publications lists of major publishers and research centers, and e) the nominations of the project's staff and a national advisory panel of recognized experts in the area of services for people with severe disabilities. Materials culled from this first step were then individually reviewed for inclusion based on the criteria outlined below.

Selection Criteria

In order to be judged as among the "best" in the field, material identified by this search had to clearly focus on the goal of socially integrating people with severe disabilities into the community. As a measure of this we evaluated each resource for the degree to which it reflected the following principles for community integration:

1. All people with developmental disabilities belong in the community. We looked for more than just an official statement of belief in the principle of the "least restrictive environment." We looked for materials that revealed a commitment to the belief that all people, regardless of the severity of disability, belong in the community.

2. People with severe disabilities should be integrated into typical neighborhoods, work environments, and community settings. Where do typical people live, work, play, go to school, and shop? This is where people with developmental disabilities, including those with severe disabilities, should do these things.

3. Support the placement of people with severe disabilities in homes and natural community settings. One of the great ironies--and tragedies--of traditional service systems is that they have undermined families. It has often been easier for parents to have their children institionalized or placed in other out-of-home settings than to receive in-home support. We looked for material which emphasized the need to maintain people with disabilities in their families or at least in their native communities.

4. Community living arrangements should by family-scale. The field of developmental disabilities has been obsessed with trying to determine the optimal size of a community residence. Is eight better than ten or ten better than twelve? It is foolish to think that small size alone, in isolation from other factors, will guarantee a high quality of life or high degree of integration. The debate about size detracts attention from this. We think community settings should be "family-scale." Hence we looked for materials

which concentrated on developing family size living situation rather than researching the optimal size of a group home.

5. Encourage the development of social relationships between people with severe disabilities and other people. "Community" is not only a place to be. It is a feeling of belonging among human beings. People with severe disabilities need friends and other people who care about them--just like other people. If there has been one thing lacking in our service systems, it is the lack of opportunities people have to develop close, mutual, and ongoing relationships with other people. We looked for materials which saw this need and attempted to address it.

6. Foster participation in community life and the development of community living skills. This principle implies two things. The first has to do with social integration. Community integration doesn't mean physical placement in the community. It also means interacting with other people in the community. The second implication relates to the opportunity to learn practical life skills. Community residences have been defined largely as places to live, rather than learn. To be sure, community settings should not be treatment centers. But, in any home, somebody has to go grocery shopping, cook meals, wash dishes, and clean the house. We looked for material which highlighted the need for people with severe disabilities to learn the functional skills they need to at least partially participate in these activities.

7. Involve parents and consumers in the design, operation, and monitoring of services. Professionals may come and go; the parents and consumers will always be there. In

practice this meant looking for materials where parents and consumers were treated not merely as passive clients, but as partners in developing services.

8. A commitment to positive interventions. It is unfortunately true that many of the behavioral strategies recommended for use with people with severe disabilities would be totally unacceptable if used with nondisabled people. We see integration as meaning that the same standards are applied for all people. With this in mind, we screened the materials we reviewed for agreement with the principles outlined in the Association for Persons with Severe Handicaps resolution on non-aversive interventions (Reprinted on page 98).

When we used these criteria, to review the massive amount of material which our literature search had identified, we discovered large gaps in the literature. A major reason for these unexpected gaps was materials which claimed to focus on community integration but on closer examination were found to merely transfer the traditional institutional approach to programming into the community. So, the materials which we selected for inclusion here reflect a certain coherent vision of what the lives of people with severe disabilities should look like and offer some innovative approaches to services.

PERSPECTIVES ON INTEGRATED COMMUNITY SERVICES

The materials reviewed in this section are intended to give the reader an overview of the historical and ideological perspectives which inform the movement to provide community-based services for all disabled persons. For that reason, these resources tend to be oriented more to addressing broad issues than to the actual provision of specific services. But, this does not mean the direct service provider or the clinician should ignore these materials. Rather, the complex nature of the forces encountered by practitioners in community settings require that they have a good understanding of the need for these services and a strong commitment to the provision of services in the community.

TITLE: Criterion of ultimate functioning

AUTHOR: Brown, L., Nietupski, J., & Hamre-Nietupski, S.

PUBLICATION INFORMATION: 1976

In M. A. Thomas (Ed.) Hey, don't forget about me: Education's investment in the severely, profoundly, and multiply handicapped. Reston, VA: Council for Exceptional Children. (pp. 2-15)

This valuable resource is currently out of print. It should be available at any library with a solid collection in the area of special education.

The case is made in this article that programs for severely handicapped individuals have been oriented towards preparing these people to function in segregated environments. The authors propose a redirection of practice in services to severely handicapped persons toward, what they call, the Criterion of Ultimate Functioning--"the ever changing, expanding, localized, and personalized cluster of factors that each person must possess in order to function as productively and independently as possible in socially, vocationally, and domestically integrated adult community environments." Some of the factors suggested to facilitate this orientation are 1) integration into heterogeneous community environments; 2) a system of services for persons with severe disabilities which are longitudinal, comprehensive, and coordinated; and 3) the use of instructional approaches that are specifically geared toward teaching needed skills in natural environments.

TITLE: Challenges of emerging leadership: community based independent living programs and the disability rights movement

AUTHOR: Funk, R.

PUBLICATION INFORMATION: 1984

The Institute for Educational Leadership
1001 Connecticut Avenue, N. W.
Suite 310
Washington, DC 20036

COST: $4.95

This document reports on the status of the independent living movement. It begins by outlining and discussing the basic principles of independent living which include 1) Disabled persons design and run their own programs, 2) These programs are community based and community responsive, and 3) These programs provide services and also undertake advocacy for change in the larger community. The history of independent living and the disability rights movement are recounted. Special emphasis is given to making clear that independent living should not be viewed as just another traditional model of services in a new wrapper. Five major operational issues which confront this movement are discussed along with some recommendations for dealing with them.

Of particular value in this paper are the basic principles and perspectives which the independent living movement conveys. These principles, the section on crucial issues, and the recommendations for the future should be read with an eye to their applicability to all disabled persons and not just as they apply to those individuals who have traditionally been identified as "candidates" for independent living.

TITLE: Developmental Disabilities: The DD Movement

AUTHOR: R. Wiegerink & J. W. Pelosi (Eds.)

PUBLICATION INFORMATION: 1979

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $10.50

This book attempts to offer a straightforward, non-technical appraisal and summary of the national DD movement. Part I describes: the nature and needs of persons with developmental disabilities, the role and function of the states DD councils, and a critique of the movement. Part II presents the core of the movement--its advocacy mission. The various levels of advocacy; system, legal, and personal, are examined. Part III deals with movement's efforts in the area of public awareness. Part IV discusses the problems of obtaining services in an uncoordinated system with particular emphasis on the need for consumer input for quality services. The final chapter charts a course for the future improvement of the service system.

TITLE: The principle of normalization in human services

AUTHOR: Wolfensberger, W.

PUBLICATION INFORMATION: 1972

National Institute on Mental Retardation
Kinsmen NIMR Building
York University
4700 Keele Street
Downsview, Ontario, Canada M3J 1P3

COST: $12.50

As one of the most significant publications in the history of services to persons with mental retardation this book remains necessary reading for anyone involved in the provision of services. The first section delineates the conceptual and historical roots of our societies traditional approach to providing services to people with mental retardation. The principle of normalization is defined and proposed as an alternative service ideology which can avoid the pitfalls of the dehumanizing practices of the past. Some of the major implications of this principle are briefly explored. In the second section the implications of the principle of normalization for a wide range of concerns, from architecture to sex, are explored. The final section explores normalization as an impetus for generic services, citizen advocacy, monitoring of services, and direct financial support for handicapped persons.

TITLE: Wanderers in a promised land: The chronically mentally ill and deinstitutionalization

AUTHOR: Freddman, R. I. & Moran, A.

PUBLICATION INFORMATION: 1984

Special Supplement to Medical Care, 22 #12

This report traces its origin to a 1982 conference on the chronic psychiatric patient conducted by the Division of Health Policy Research and Education of Harvard University. While this report is not focused on persons with developmental disabilities, the policy recommendations in section 7 "Who manages the system of services?;" section 8 "Who pays for these services?;" and in the Executive Summary under "Administrative Responsibilities," "Fiscal/Management Policies," and "Legislative Action" are worth reviewing. Essentially, these recommendations call for a more coordinated approach to services, the conversion of fiscal resources to the community, and a more responsive system of quality assurance.

TITLE: The family papers: A return to purgatory

AUTHOR: Blatt, B., Ozolins, A., & McNally, J.

PUBLICATION INFORMATION: 1979

New York: Longman

This valuable resource is currently out of print. It should be available at any library with a solid collection in the area of special education.

In 1966, Burton Blatt and Fred Kaplan, the former a respected professional in the field of mental retardation and the latter a photographer, shocked America's conscience with the publication of Christmas in Purgatory, a photographic expose of conditions in institutions for people with mental retardation. Ten years later, Blatt, this time with Andrejs Ozolins and Joe McNally, returned to these institutions to document the changes and reforms that had occurred since the earlier expose. The findings are contained in The Family Papers. Filled with photographs of institutions and alternative settings, this book at once documents improved conditions at institutions and captures the more subtle forms of dehumanization which occur there today. As the authors conclude, "As you will see, everything has changed during the last decade. As you will see, nothing has changed." The book presents a compelling argument in favor of community living. Policymakers, parents, and professionals new to the field will find this book especially informative.

TITLE: Severely handicapped persons in the community

AUTHOR: C. L. Hansen (Ed.)

PUBLICATION INFORMATION:

Program Developmental Assistance System
University of Washington
1107 NE 45th Street
Suite 330
Seattle, WA 98105

This edited volume provides a nice overview of the issues involved in establishing community integration programs for people with severe disabilities. The articles in this book address philosophical issues, service system principles, model program descriptions and some practical ideas. The chapters include: (1) Perspectives in Communitization; (2) How Parents can Affect Communitization, or What Do You Mean I'm a Troublemaker; (3) School and Community Inclusion: The Public Schools of Tacoma, Washington; (4) Overcoming Obstacles to the

Personalization of Services; (5) Your Place or Mine: Residential Options for People with developmental Disabilities; (6) Residential Caregivers and Public School Teachers of Severely Handicapped Children and Youth; (7) Improving Vocational Services Through Interagency Cooperation; and (8) Achieving Communitization Objectives: From Blind Faith to Wide-Eyed Reality.

TITLE: Normalization, social integration, and community services

AUTHOR: R. J. Flynn & K. E. Nitsch (Eds.)

PUBLICATION INFORMATION: 1980

PRO Ed
5341 Industrial Oak Boulevard
Austin, TX 78735

COST: $16.00

This is an edited book that provides a comprehensive review of the principle of normalization. The book is divided into three parts. Part I, "The Normalization Principle: Systematic Statements and Clarifications," includes articles authored by Wolf Wolfensberger, Bengt Nirje, and Neils E. Bank-Mikkelsen which provide an update on the meaning of normalization and address common misconceptions of the principle. Part II, "The Normalization Principle: Implications for Legislating, Implementing, and Evaluating Community Services," contains ten separate articles which deal with legal issues (especially, the implications of the Pennhurst case), special education (a classic article on least restrictive educational environments written by Lou Brown and others), early childhood education, the research on community residential settings, vocational service,regional planning for "communitization," a "supermarket of services" for elderly adults, and program evaluation based on normalization. Part III of the book contains a conclusion by the editors and a comprehensive bibliography of normalization references. Policymakers, planners, and administrators will most find this book useful.

TITLE: Mental retardation: The leading edge, services that work

AUTHOR: Perske, R.

PUBLICATION INFORMATION: 1979

The President's Committee on Mental Retardation
Superintendent of Documents
U. S. Government Printing Office
Washington, DC 20402
DHEW Publication No. (OHDS) 79-21018

The book highlights 30 effective service programs for mentally retarded persons. The first section presents information on eight family oriented programs serving high risk, Down's syndrome, urban poor, and profoundly handicapped children. Included are descriptions of parent education, support, and advocacy programs. Among seven public school education programs summarized include a preschool program in which normal children are integrated, a merger between a special school and a regular one, a community centered program for hearing impaired retarded teenagers, and continuing education courses on college campuses. Among the five community residence programs represented are the Eastern Nebraska Community Office of Retardation, the Macomb-Oakland Regional Center (Michigan), and the Tuolumne County Independent Living Project (a rural California program). Three descriptions of effective vocational programs are followed by two self assertion projects. Two programs serving mentally retarded offenders and two serving mentally ill/mentally retarded persons are reviewed. Final sections touch on prevention and future issues (including consumer advocacy systems, special-regular teacher relationships and local community responsibility).

TITLE: The Willowbrook wars: A decade of struggle for social justice

AUTHOR: Rothman, D. J. & Rothman, S. M.

PUBLICATION INFORMATION: 1984

New York: Harper and Row

COST: $27.95

This book traces the history of reforms and litigation at the infamous Willowbrook State School in Staten Island, New York from 1972 to 1983. While the book focuses on the specific experience at Willowbrook, it has general relevance to the issues of institutional reform, the impact of courts on service systems, parent involvement, deinstitutionalization, and community-based services for people with severe disabilities.

Practically everyone involved in services for people with severe developmental disabilities will find The Willowbrook Wars interesting and useful. Parents will identify with the heart-wrenching experiences and dilemmas of parents of people at Willowbrook. Policy makers and planners will find important lessons about the complexity of reform, systems change, and developing community services. Attorneys and advocates will gain additional insight into the impact of their activities. Service providers will learn about approaches for gaining community acceptance, designing humane and effective programs, planning strategies, the importance of independent monitoring, and current controversies over issues like the size of community living arrangements and community fears of "Hepatitis B carriers." Written in clear language and an engaging style, The Willowbrook Wars is "must" reading for people interested in community integration programs. It is one high-priced book well worth the cost.

TITLE: Strategies for achieving community integration of developmentally disabled citizens

AUTHOR: Lakin, K. C., & Bruininks, R. H. (Eds.)

PUBLICATION INFORMATION: 1985

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $24.95

This book focuses less on the analysis of the nature of community integration and more on how, in practical terms, to achieve it. Community integration raises a complex web of issues. The authors go a long way toward communicating this complexity and address an extraordinary range of critical issues with uncommon care and detail. The volume examines such issues as the deinstitutionalization policies, the insufficient coordination of services, the lack of opportunities for integrated work, critiques the commonly used behavioral teaching strategies, and looks at model programs in school integration and leisure and recreation. Indicative of the range and relevance of the volume, the editors have sensibly chosen to emphasize economic considerations and the book affords an invaluable superb explanation of federal income/insurance programs demonstrating their penchant to militate against people with mental retardation entering the work force. It also reveals the complexity of community integration funding strategies and the Medicaid/medical model dilemma.

To our benefit, this volume implores us to ask fundamental questions: about what actually constitutes state-of-the-art; the re-emergence of the medical model; growing bureaucratization of services; the role of professionals in the lives of persons labeled mentally retarded; and the day-to-day experiences of people with severe disabilities.

This book should be of great interest to all who are interested in how to achieve community integration. It provides indepth and far-reaching examination of both the principal, complex barriers to integration and many of the current responses to them.

TITLE: Living and learning in the least restrictive environment

AUTHOR: R. H. Bruininks & K. C. Lakin (Eds.)

PUBLICATION INFORMATION: 1985

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $22.95

Recently, the literature has reflected a growing recognition that deinstitutionalization and its complement community integration raises a complex web of issues about disabilities, society's tolerance for difference, the nature of large scale social change and resistance to it, and many others. Throughout this book the various authors concur with one another that any difficulties which attend deinstitutionalization relate to methods of achieving community integration and not to the legitimacy of the goal itself. The authors address extraordinary range of critical issues with uncommon care and detail. The book provides indepth and far-reaching examination of both the principal, complex barriers to integration and many of the current responses to them.

As the editors note, progress toward community integration has occurred slowly. These may be myriad explanations for the slowness and questionable quality of deinstitutionalization, a policy that has prevailed in the nature for more than decades. This volume examines many of these. This book should be of great interest to all who want to explore the nature of community integration.

FUNDING INTEGRATED COMMUNITY SERVICES

The major source of funding for programs for people with the most extensive service needs has been Title XIX of the Social Security Act, Medicaid. For that reason, the bulk of the material in this section focuses on that program. The resources in this section review: the origins of Medicaid, its growth, where and how it has been used for service to people with developmental disabilities, the constraints which it imposes on community programs, the Medicaid waiver as an attempt to gain some flexibility in services, and proposals for restructuring Medicaid. In addition, this section includes a major report on public expenditures for institutions and community services nationally.

TITLE: Implementation of the home and community-based waiver

AUTHOR: Gardner, J. F.

PUBLICATION INFORMATION: 1986

Mental Retardation
24(1), 18-26.

The success of states in developing home and community-based service waivers authorized by the 1981 amendments to the Social Security Act contained in PL 97-35, the Omnibus Reconciliation Act, was examined. Many states submitted waiver proposals that provided a wide range of community-based services to persons who would otherwise require care in an Intermediate Care Facility for the Mentally Retarded. Most states integrated the waiver services into the existing pattern of service delivery. Difficulties in complying with federal requirements, however, have delayed implementation of the waiver program in many states.

TITLE: Direct cost of institutional care in the United States

AUTHOR: Braddock, D., Hemp, R., & Howes, R.

PUBLICATION INFORMATION: 1986

Mental Retardation
24(1), 9-17.

The design and results of a nationwide study of the costs of institutional care in the United States between FY's 1977 and 1984 were summarized. Important trends identified were: (a) a plateau in adjusted total nationwide spending for institutional operations, (b) a decline in adjusted nationwide spending for institutions from state revenue sources, and (c) the emergence of the federal government as an equal partner with the states in financing of state institutions. The study also confirmed, through June 30, 1984, the continuing annual reduction in the institutional census and the steady climb in per diems. For the first time, the nationwide per diem exceeded $100 (in 1984). Given the average annual rate of decline since 1977, the nation's institutional census will fall below 100,000 in FY 1986.

TITLE: Changing Medicaid and intermediate care facilities for the mentally retarded (ICF/MR): Evaluation of alternatives

AUTHOR: Fernald, C. D.

PUBLICATION INFORMATION: 1986

Mental Retardation
24(1), 36-42

Medicaid-ICF/MR, the largest source of federal funds for persons with mental retardation, primarily benefits the residents of large institutions. There is a national interest now in modifying the ICF/MR program to encourage more use of Medicaid resources for home and community-based care. Some alternatives for changing ICF/MR were evaluated in this paper, and a model that can be used for considering other alternatives was presented. Attractive proposals include a system of treatment protocols for diagnosis-related groups and a revision of S.873, The Community and Family Living Amendments of 1985.

TITLE: Resource allocation approach for determining clients' need status

AUTHOR: Schalock, R. L. & Keith K. D.

PUBLICATION INFORMATION: 1986

Mental Retardation
24(1), 27-35.

Procedures and exemplary results for a resource allocation approach to determining clients' need status were outlined. Procedures were summarized whereby measured client characteristics can be used to determine whether a client is high, moderate, or low need status based upon a significant relationship between measured characteristics and needed staff time. These characteristics have been identified for Intermediate Care Facilities for the Mentally Retarded and Community-Based Mental Retardation environments. The authors proposed that this approach results in standard client characteristic data that are helpful in evaluating relevant programmatic, cost, and outcome variables. A number of exemplary uses were presented and potential problems discussed.

TITLE: Developing financial incentives for placement in the least restrictive alternative

AUTHOR: Copeland, W. C. & Iversen, I. A.

PUBLICATION INFORMATION: 1985

In K. C. Lakin & R. H. Bruininks (Eds.) Strategies for achieving community integration for developmental disabled citizens. Baltimore: Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

The authors of this article suggest that the way most states and the federal government fund services for people with developmental disabilities tend to be uncoordinated and may actually hinder integration. A strong case is made for an approach to funding which is tied to individuals rather than solely to programs. A model state budget is used to show how funds can be redirected in a manner which will support integration.

TITLE: A comparison of Medicaid waiver applications for populations that are mentally retarded and elderly disabled.

AUTHOR: Lakin, K. C., Greenberg, J. N., Schmitz, M., & Bradley, K. H.

PUBLICATION INFORMATION: 1984

Mental Retardation
22(4), 182-192

This article provides an in-depth examination of state application for Medicaid waivers for home and community-based services. It includes a state-by-state breakdown of home and community-based services funded under the waiver, populations served, and methods of showing cost savings. The information presented in this article is based on approved waiver applications as of February, 1983 and may be outdated.

TITLE: Federal funding of community services: Can the Medicaid waiver help?

AUTHOR: McGregor, G.

PUBLICATION INFORMATION: 1983

Journal of The Association for the Severely Handicapped 8(2), 56-64.

This article describes the rationale and provisions of the Medicaid home and community-based waiver authority. The article also describes the status of state waiver applications as of April 1983, although much of this information is outdated by now. The conclusion of the article considers the potential impact of the Medicaid waiver on community services.

TITLE: The Medicaid Home and Community-Based Waiver Authority

AUTHOR: National Association of State Mental Retardation Program Directors, Inc.

PUBLICATION INFORMATION: 1981

National Association of State Mental Retardation
Program Directors, Inc.
2001 Jefferson Davis Highway
Arlington, VA 22202

COST: $10.00

Written for state program directors, this is an excellent reference work on the so-called "Medicaid waiver," passed in 1981 to provide federal reimbursement for a broad range of home and community-based services. This report describes the background of the Medicaid waiver, lists the conditions for approval of the waiver, explains eligibility criteria, lists reimbursable services, and provides other information on this funding source for community services. The Appendix contains a copy of federal regulations for the waiver program. Since this report was written before the federal and state governments had any experience with the Medicaid waiver, some of the information may be outdated. It nevertheless provides a good starting place for exploring the use of Medicaid funds for home and community-based services.

TITLE: Medicaid dollars and community homes: The community ICF/MR controversy.

AUTHOR: Taylor, S. J., McCord, W., & Searl, Jr., S. J.

PUBLICATION INFORMATION: 1981

Journal of The Association for the Severely Handicapped
6(3), 59-64.

This article examines the controversy surrounding the use of Medicaid ICF/MR funds to support community programs for people with developmental disabilities. After a brief introduction, the article provides an overview of the history of the ICF/MR program and describes how this program has encouraged states to invest resources in institutions. The article next moves to a consideration of the pros and cons of using ICF/MR funds for community residential settings. In the conclusion, the authors offer a series of recommendations for funding community settings through the ICF/MR program.

TITLE: Expansion of the Medicaid ICF-MR program over a five-year period, 1977-1982 (Working Paper 25)

AUTHOR: Lakin, K. C. & Hill, B. K.

PUBLICATION INFORMATION: 1984

Center for Residential and Community Services
University of Minnesota
Department of Educational Psychology
207 Pattee Hall
150 Pillsbury Drive, S. E.
Minneapolis, MN 55455

This report describes the growth in the ICF/MR program over a five-year period. The report documents trends in ICF/MR services broken down by state. This report is filled with demographic information on the number of people living in ICF/MR certified facilities, the costs of services, and other information. Planners and policy-makers, rather than administrators and service providers, will most find this report useful.

TITLE: Public expenditures for mental retardation and developmental disabilities in the United States: State profiles (Public Policy Monograph Series Number 5)

AUTHOR: Braddock, D., Kemp, R., & Howes, R.

PUBLICATION INFORMATION: 1984

Expenditure Analysis Project
Evaluation and Public Policy Program
Institute for the Study of Developmental Disabilities
University of Illinois at Chicago

COST: $25.00

This is a 882-page report that provides a detailed state-by-state breakdown of expenditures for mental retardation and developmental disabilities services. The report contains a brief introduction on methodology and three major parts. Part one contains national and comparative information on expenditures for institutional and community services, revenue sources for institutional and community services, ICF/MR reimbursements, and daily expenditures and population trends. This part of the report provides a good overview of national trends and a quick comparison of how the 50 states and the District of Columbia fare in terms of expenditures for institutional versus community services and institutionalization and deinstitutionalization trends. Part Two provides an in-depth look at expenditures, revenue sources, institutional population trends for each state and the District of Columbia. Part Three of the report provides a brief description of federal and/or state expenditures for Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and the Education for All Handicapped Children Act, P.L. 94-142. This report is extremely well organized and easy to understand. Most of the information contained in the report is presented through simple and clear charts and figures.

The report is not a manual on how to fund services for people with mental retardation and developmental disabilities. However, many policymakers, administrators, parents, and others will find this report extremely useful and illuminating. It provides answers to questions regarding where federal and state dollars are going and how states compare with one another. This report is the most comprehensive and detailed analysis of national and state expenditures published to date.

TITLE: Federal administrative constraints on state Medicaid outlays for mentally retarded and other developmentally disabled recipients: A state-by-state survey report

AUTHOR: Gettings, R. M. & Salmon, S.

PUBLICATION INFORMATION: 1985

National Association of State Mental Retardation
Program Directors, Inc.
113 Oronco Street
Alexandria, VA 22314

This is a comprehensive and up-to-date report on the status of federal Medicaid funding of programs for people with developmental disabilities. Based on a review of federal policies, a survey of state officials, and other sources, this report addresses major policy issues in the ICF/MR program, the Medicaid home and community care waiver program, and other Medicaid programs targeted at people with developmental disabilities. The report contains four major sections. The first, addresses federal ICF/MR disallowances. The second section contains an update on home and community care waivers and describes the problems states are facing in having Medicaid waivers approved or extended. The next section describes federal "ICF/MR Look Behind Surveys" designed to monitor compliance with ICF/MR standards. The final major section discusses problems states are experiencing in obtaining federal approval for Medicaid reimbursement for clinic, rehabilitation, and personal care services. The Conclusion of the report suggests that expanded federal oversight of the ICF/MR and Medicaid waiver programs may be a "smokescreen" for attempts to reduce federal Medicaid expenditures, rather than to insure high quality services. The appendices of the report also contains listings of state contact persons for obtaining information about various aspects of state Medicaid programs. Written for state mental retardation program directors, this report is an important resource for anyone interested in using federal Medicaid funds to support services for people with developmental disabilities.

TITLE: Restructuring Medicaid: An agenda for change: Summary Report

AUTHOR: National Study Group on State Medicaid Strategies

PUBLICATION INFORMATION: 1984

Center for the Study of Social Policy
236 Massachusetts Avenue, N. E.
Suite 405
Washington, DC 20002

COST: $5.00

The study group, which wrote this report, was formed in 1982 to develop comprehensive strategies to help control Medicaid cost and to increase access to quality service for persons dependent on Medicaid. They review the growth of Medicaid with particular focus on how it grew in totally unintended directions. They call for a radical reordering of this system into two very different systems: 1) a national primary health care program and 2) a continuing care system to meet the needs of individuals with a functional impairment (e.g., the disabled elderly and persons with developmental disabilities). They present a detailed description of these two proposed systems and end by developing a financing plan for both.

Of particular interest to the planner and administrator is this report's analysis of the strength and weaknesses of the current system. What stands out is the inappropriate constraints which Medicaid funding has imposed on the attempts to develop innovative, community-based services for disabled persons. At the very least reading this report should motivate a thoughtful examination of the way this funding stream has determined the nature of many of our services.

A companion volume of "Background papers" is available for $5.00 from the same source. These papers include: 1) a policy perspective on the Medicaid program, 2) the provision of health services, 3) policy choices in long term care and 4) the role of Medicaid in the provision of care for the developmentally disabled.

PLANNING AND COORDINATING A COMPREHENSIVE COMMUNITY SERVICE SYSTEM

The ability of people with the most severe disabilities to survive and flourish in their natural communities is largely dependent on the availability of a full range of services in those communities. The resources in this section provide conceptual frameworks, lists of service principles, catalogues of necessary services, and strategies and resources to use in managing and coordinating a comprehensive system of services.

TITLE: Surviving in the system: Mental retardation and the retarding environment

AUTHOR: People First of California

PUBLICATION INFORMATION: 1984

Capitol People First
6835 Wavecrest Way
Sacramento, CA: 95831

COST: $7.50

This document was produced by People First of California, a state-wide self-advocacy organization under contract with the California State Council on Developmental Disabilities. The document describes the methodology and results of a needs assessment based on consumer-to-consumer interviews, describes a model for individuals with disabilities to use in their efforts to organize self-advocacy groups or to become better self-advocates, and includes very specific recommendations to public and private agencies and policy making bodies in California on how change can best be effected.

The central theme throughout the document is one of self-advocacy and overcoming the "retarding environment." The authors stress the point that the current service system often does little to promote self-growth and independence, and often discourages and impedes independence.

This book offers a great deal to a wide variety of readers. It obviously is a great value to consumers and their families. It is also an important document to be read by professionals, policy makers and students of human services.

TITLE: The closure of mental retardation institutions
I. Trends in the United States
II. Implications

AUTHOR: Braddock, D. & Heller, T.

PUBLICATION INFORMATION: 1985

Mental Retardation
23(4), 168-176; 23(5), 222-229.

Twenty-four mental retardation institutions in the United States have closed or are soon scheduled to close. In Part I, it is pointed out that the closure of institutions is primarily the product of long-term trends toward community services development and economic factors constraining state government expenditures. Part II reviews outcome studies of the impact of closure and involuntary relocation on clients, families, and employees.

Interim results of the Dixon Developmental Center Longitudinal Closure Study are also presented, along with suggested closure guidelines emanating from that study. In conclusion, the implications of institutional closure as an emergent national trend in the field are discussed, and suggestions for future study are delineated.

TITLE: Direction services: A model facilitating secondary prevention of developmental handicapping conditions

AUTHOR: Davidson, P. W., Reif, M. E., Shapiro, D., Griffith, B. F., Shapiro, P. F., & Crocker, A. C.

PUBLICATION INFORMATION: 1984

Mental Retardation
22(1), 21-27.

This article describes a model program for direction service for infants and preschool children with or at risk for developing a handicapping condition. The model, implemented and evaluated in Western New York State, ties together the health care and educational-habilitative systems to facilitate a continuity of comprehensive service provision from birth through school age, increase the total community effort regarding identification, and links identification with the direction counseling and referral process. The model is discussed in terms of its general characteristics, replicability, and its impact on secondary prevention of developing handicapping conditions.

TITLE: Creating responsive communities: Reflections on a process of social changes

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1985

Ontario Association for
the Mentally Retarded
376 Bayview Avenue
Toronto, Ontario, Canada M4G 3A3

This monograph is about the struggle to create more responsive communities for people with developmental handicaps and their families. In Ontario, Canada, this struggle took the form of ComServ, an acronym for comprehensive, community-based services, is a social change strategy developed in 1972. In its simplest form, the goal of ComServ is to provide every handicapped individual with a place in their community where they can go to be assured that high quality services which are comprehensive to their needs will be developed. In another sense, ComServ is about how regions can plan services with individuals and families to ensure that services are valued, individualized, and as integrated as possible.

This monograph has three major sections. Part One documents the history of of the ComServ movement in Ontario, including an analysis of the various initiatives which led people in the 1970's to be concerned about issues which go beyond direct service provision. Part Two provides an analysis and assessment of more recent critical issues and actions from the social change process, including major themes, principles, and processes which have worked and some of those which have faced difficulties. And finally Part Three reflects on how the nature of ComServ has been revised as people's understanding has expanded and as political-economic contexts have changed.

TITLE: Culturing commitment

AUTHOR: Provencal, G.

PUBLICATION INFORMATION: In Press (To be published Spring 1987)

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.) Community integration for people with severe disabilities. Teachers College Press, 1234 Amsterdam Ave., New York, NY, 10027.

This article shares the views and experiences of Gerald Provencal, Director at Macomb-Oakland in Michigan, on how to maintain commitment in human services. It place a strong emphasis on the role of the dynamic leadership and commitment to a clear set of principles. Within this context he attempts to de-bunk what he sees as the myths surrounding community integration and burn-out.

TITLE: From institution to community: A conversion model

AUTHOR: Blatt, B., Bogdan, R., Biklen, D., & Taylor, S. J.

PUBLICATION INFORMATION: 1977

In E. Sontag, J. Smith, & N. Certo (Eds.) Educational Programming for the Severely and Profoundly Handicapped. Reston, VA: Council for Exceptional Children.

This article provides a conceptual model for deinstitutionalization. The authors propose the concept of "conversion" as an alternative to deinstitutionalization, which simply means the release of persons from institutions. They define conversion as "an orderly transition from an institutional to a community-based system of services with concomitant plans to transform existing physical facilities, staff resources, institutional ideologies, community attitudes, and agency policies to alternative, more humanizing uses and postures." The article describes administrative, economic, and attitudinal barriers to the establishment of a system of community services. Policymakers, planners, and state and regional administrators will find this article the most useful.

TITLE: Annotated bibliography of literature on planning comprehensive, integrated service delivery systems for children with special needs and their families

AUTHOR: Barber, P., Behr, S., Hazel, R., & Helmstetter, E.

PUBLICATION INFORMATION: 1984

The NEXUS Project
Department of Special Education and the
University Affiliated Facility in the Bureau of
Child Research
University of Kansas
Lawrence, KS

This is a comprehensive annotated bibliography of books, manuals, articles, and other resources on integrated community-based service delivery systems for severely disabled and chronically ill young children. The bibliography lists 108 separate references and is divided into two sections: (1) service system planning; (2) service integration.

Although this bibliography focuses on services for young children and their families, many of the references are applicable to community-based service systems for other populations. The bibliography contains most major resources on interagency coordination and cooperation. State agency officials and technical assistance providers will find this bibliography most useful.

Of the many works annotated in this bibliography, the following are most relevant to community service systems for people with severe disabilities:

* A guide to Local Implementation (Vol. II of Interagency Collaboration on Full Services for Handicapped Children and Youth)
* Analyzing Costs of Services
* Comprehensive Planning for Human Services
* Comprehensive Planning: Standards for Advocacy
* Planning for Services to Handicapped Persons: Community Education, Health
* Agencies Working Together: A Guide to Coordination and Planning

- * A Guide for Creating Community Awareness and Developing Interagency Cooperation
- * A Handbook for Interagency Collaboration
- * Coordinating Human Services
- * Developing Program Models for the Human Services
- * Guidelines for Interagency Cooperation and the Severely Disabled
- * Human Services and Resource Networks: Rationale, Possibilities, and Public Policies
- * Perspectives on Interagency Collaboration
- * Toward Human Service Integration: A Proposed Methodology for Coordination of Human Services

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TITLE: Deinstitutionalization of developmentally disabled persons: A conceptual analysis and guide

AUTHOR: Bradley, V. J.

PUBLICATION INFORMATION: 1978

Baltimore: University Park Press

COST: $9.75

The book was written to assist state and local policymakers, administrators, and service providers who have been given responsibility for shifting from an institutional or custodial system of services for developmentally disabled citizens to more dynamic, habilitative, and affirmative modes of care. It is meant to clarify the goals of system improvement in the field and to identify the principal problems of implementation that have bedeviled both program managers and would be reformers over the past several years.

The book considers the social, ideological, political, and programmatic factors that have influenced and continue to shape the movement away from large institutions to small community-based settings in the field of developmental disabilities. It provides a mode for assessing deinstitutionalization at the state and local levels by highlighting the context in which these changes must take place, the planning that can assist in directing such change, and the key elements that must be present in the implementation stages in order to ensure a systematic and beneficial result.

TITLE: Keeping the promise of the Lanterman Act, Report 1: Quality services for people with developmental disabilities

AUTHOR: Galloway, C.

PUBLICATION INFORMATION: 1984

State of California
Joint Publications Office
Box 90
State Capitol
Sacramento, CA 95814

COST: $7.90

This is a report about the history and implementation of the Lanterman Developmental Disabilities Act. The law intended to serve developmentally disabled people in ways that support families and encourage community integration. The report studies funding methods, quality assurance procedures, organizational problems and makes recommendations about California's Service system.

TITLE: The Pennhurst Longitudinal Study: Combined report of five years of research and analysis

AUTHOR: Conroy, J. W. & Bradley, V. J.

PUBLICATION INFORMATION: 1985

Temple University
Developmental Disabilities Center
9th Floor, Ritter Hall Annex
Philadelphia, PA 19122

COST: $15.00

This book provides the results of a five-year study about the Pennhurst litigation (Halderman v. Pennhurst State School and Hospital, 1977) and considered the following aspects: determines the impact of relocation on mentally retarded persons; assesses the impact of deinstitutionalization on families of people with developmental disabilities; compares the costs of providing services in the institution to those in community settings; assesses the legal history of the Pennhurst case; and addresses various other issues in connection with the district court's decree and the implementation. The study is organized into three major parts: 1) A section which assessed the quality of living environments, level of satisfaction and services received by residents both in Pennhurst and in the community. 2) A section which provides average costs per unit of service at Pennhurst and in the community, as well as estimates of total costs for each relocated client as a function of how much service the client actually received. 3) This section investigated the interrelationships among events and key system actors, as well as the implications for state and federal policy.

TITLE: Planning community services using the Title XIX waiver as a catalyst for change

AUTHOR: Karan, O. C. & Gardner, W. I.

PUBLICATION INFORMATION: 1984

Mental Retardation
22(5), 240-247

This article has a somewhat misleading title. It does not describe the federal Medicaid waiver for home and community-based services. Rather, the authors use the Medicaid waiver as an introduction to guidelines for community program planners. They provide six sound principles or guidelines for developing community services. Each guideline is supported by a review of research findings.

TITLE: Shaping the future: Community-based residential services and facilities for mentally retarded people

AUTHOR: P. Roos, B. M. McCann, & M. R. Addison (Eds.)

PUBLICATION INFORMATION: 1980

Pro Ed
5341 Industrial Oak Boulevard
Austin, TX 78735

COST: $10.00

This book is the proceedings of a 1978 conference on community-based services, sponsored by the National Association for Retarded Citizens. It provides a detailed overview of the programmatic and legal issues surrounding community-based residential services. The book discusses the underlying principles and presents the components of an adequate, integrated community service system that includes residential services. It is particularly helpful for professionals and advocates in the way it: identifies obstacles to program development and the value issues behind them; emphasizes the necessity of posing the proper questions and recommendations to the court when litigation is necessary; discusses methods and strategies for implementing a favorable court order.

The book is rich in information on strategies for establishing residential facilities and services, the use of the courts to obtain the programs and services needed by mentally retarded people, and fundamentals of effective services in the community setting.

TITLE: Interagency collaboration in providing vocational education for handicapped individuals

AUTHOR: Albright, L., Hasazi, S. E., Phelps, L. A., & Hull, M.

PUBLICATION INFORMATION: 1981

Exceptional Children
47, 584-589

This article identifies the interagency agreement as a crucial element for facilitating the movement of handicapped persons from school to post school environments. While essentially a report of research which examined how interagency agreements were used, this article contains a practical checklist to provide a guide in the development of such agreements. This guide is certainly applicable to any situation which requires the cooperation of several agencies to meet an individual's service needs.

TITLE: Prevention of institutional admissions and returns (especially those due to client behavioral difficulties)

AUTHOR: Leismer, J.

PUBLICATION INFORMATION:

Available from Author
1060 Nokomis Way
Pontiac, MI 48054

The title of this paper is somewhat misleading--it is not focused on providing services to persons with serious behavior problems. The author offers a brief outline of the 12 factors which he feels are necessary for any viable community-based service system. The point is that in such a system the need to institutionalize anyone would be precluded.

The elements discussed in this paper include: 1) a philosophical orientation which rejects institutionalization as part of the "continuum" of services, 2) the proactive development of a comprehensive array of services, 3) funding determined by individual need, 4) small residential settings, 5) adequate well trained staff, 6) good case management (i.e., small case loads),

7) ample age-appropriate and need-appropriate day programs, 8) meaningful involvement in life of the community, 9) providers who are prepared to meet clients' specific needs, 10) effective individual program plans, 11) respite services, and 12) specialized programs to aid client transition from institutions (8 elements of such programs are listed).

TITLE: Interagency and interdisciplinary approaches to meeting needs of developmentally disabled

AUTHOR: Kirchman, M., et al.

PUBLICATION INFORMATION: 1979

ERIC Document ED 176 510

The document reports on the Communitization Integration Team, a joint interagency planning project whose major goal was to develop, within a two county area, models for the cooperative delivery of community based services to school age developmentally disabled children, particularly the severely-profoundly retarded. Initial sections cover project goals (including a public education-public awareness program) and the development of services in a rural county. Project planning methods are reported in a third section. The role of the team in planning the school program is discussed in terms of four major goals (among which is the development of a full service plan to meet the individualized education program needs of the students). Section 5 considers the status of services at the beginning of the project, the role/program of the training center for mentally retarded persons and constraints on joint programming. Final sections review public education efforts of the team to foster normative interactions for trainable and severely mentally retarded students, and the format and design of services developed in a rural county.

TITLE: A proactive program planners guide to community services development from an ecological point of view

AUTHOR: Karan, O. C. & Gardner, W. I.

PUBLICATION INFORMATION: 1983

ERIC Document 233 544

The paper considers the role of program planners in ensuring community adjustment of deinstitutionalized severely mentally handicapped persons, especially in light of the provisions of the Budget Reconciliation Act of 1981, which provides a waiver authority to states to increase community programs for the deinstitutionalized population. The paper adopts an ecological view in which the interaction of environmental and individual factors is emphasized. Planners are advised to be proactive, that is, to take the initiative in developing more community resources and alternatives. Among system obstacles cited to deinstitutionalization are lack of staff training, staff recruitment and retention, bureaucratic red tape, and negative attitudes. Suggestions are made for preparing for the transition from institution to community, including facilitating supportive interagency relationships.

Although this paper mentions the Medicaid waiver as a funding vehicle, the value of its suggestions are not dependent on the use of Title XIX funds.

TITLE: Independent living for the physically disabled

AUTHOR: Report of HUD Project

PUBLICATION INFORMATION: 1977

ERIC Document 136 470

Findings are presented from a one-year planning study of independent living for severely physically disabled persons. Funded by a federal grant through the city and country of Denver, the study focuses on the following 10 necessary services (with subtopics in parentheses): income assistance (subsidies and typical expenditures), attendant care (recommendations for long-term solutions and a sample budget for a cluster client), medical services (health insurance and health planning), counseling (the effects of the 1973 Vocational Rehabilitation Act), transportation (the Urban Mass Transit Administration), education (mainstreaming), employment (architectural and psychological barriers), recreation (active vs. passive involvement), housing (financing and detailed design standards), and legislation (antidiscrimination laws). Each chapter lists specific recommendations. The report also contains results of two surveys concerning the disabled population of Denver. Among four appendixes is the format of the needs assessment survey.

TITLE: Personalized living: Homes for Californians with special developmental needs

AUTHOR: Human Service Associates

PUBLICATION INFORMATION: 1979

California State Council on Developmental
Disabilities
1517 L Street, Suite 100
Sacramento, CA 95814

This report was commissioned by the California Council on Developmental Disabilities to provide a broadscale view of residential services for citizens with special developmental needs. It includes analyses of past patterns, current practices, and future opportunities, and proposes a developmental strategy for creating a future living arrangements system which is normalizing, cost-effective, humane, and consistent with relevant public policy. It also is intended to present materials that will be useful in future research and development activities concerning residential services.

A process is described for developing a system which should provide more personalized lifestyles to people with special developmental needs. A personalized model must permit stimulating, meaningful lives for service consumers while operating in harmony with our complex society, regulated as it is by intertwined mechanisms that are legal, economic, and value based. An essential ingredient of this report, consistent with the most fundamental of the democratic principles which govern our society, is the assumption that all citizens deserve a home which maximizes their personal ability to lead satisfying, self-directed lives while contributing to the common good.

The intended readership for this report includes state department administrators, legislators, government agents, service providers, consumers, and other interested citizens. There is much valuable information in this report which can assist any state or region in planning its system of services.

SERVICES: COMMUNITY LIVING

The fulcrum of a severely handicapped person's life is their home. This need for a stable secure home is the same for all people. Unfortunately, severely disabled people often find that their need for supports in the home transforms their place of residence into a "service setting." The bulk of the material in this section describes programs which, for the most part, attempt to consciously grapple with this tension. Several other programs are included which use a "home-like" service model to facilitate their clients' movement back to their natural home or into a foster home. A final group of resources address the practical issues of setting up and "managing" a home.

It should be noted that some of the materials reviewed seem to regard "group homes" as the model for providing homes for people with severe handicaps. We seriously question this point of view. It seems to be yet another instance of a model of services taking precedent over the unique needs of individuals.

TITLE: A user's guide to community entry for the severely handicapped

AUTHOR: Pancsofar, E., & Blackwell, R.

PUBLICATION INFORMATION: 1986

Albany, NY: State University of New York Press

SUNY Press
P.O. Box 6525
Ithaca, NY 14850

COST: $14.95, paperback; $39.50, hardcover

This book is an extremely valuable resource for residential planners, administrators and service providers currently faced with the challenge of developing residential options for severely handicapped individuals. It is also an important and informative resource for consumers, families, and students.

Beginning with a philosophic commitment to the principle that all individuals have a right to live in their home community, the authors provide a comprehensive overview of residential options. In addition, they address topics such as evaluation of community living options, financial considerations, funding sources, and community resources, among others. Included are a number of practical activities, worksheets and checklists, as well as instructional strategies for training in specific areas of independent living skills.

TITLE: Embracing ignorance, error and fallibility: Competencies for leadership of effective services

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: In Press (To be published Spring 1987)

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.) Community integration for people with severe disabilities. Teachers College Press, 1234 Amsterdam Ave., New York, NY, 10027.

In this chapter the author highlights the fact that the way that many managers have traditionally thought about human services can be counter-productive for the integration of people with severe disabilities. As an alternative he suggests that the most innovative service systems are willing to learn from their own ignorance, errors and fallibility. This perspective is well illustrated with three extensive case studies of systems in the process of changing to an individualized approach to services.

TITLE: Life is just what you make it

AUTHOR: Rucker, L.

PUBLICATION INFORMATION: In Press (To be published Spring 1987)

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.) Community integration for people with severe disabilities. Teachers College Press, 1234 Amsterdam Ave., New York, NY, 10027.

This chapter presents the perspective of Lyn Rucker, the Executive Director of Nebraska's Region V, on how an individualized community based program was developed in a rural area for a number of people with very severe disabilities. This discussion is prefaced with an outline of the underlying principles which guided this development. As a conclusion the author points out what did and did not work in this region and offers specific suggestions for other regional planners.

TITLE: Belonging to the community

AUTHOR: Johnson, T. Z.

PUBLICATION INFORMATION: 1985

Options in Community Living
1954 East Washington Avenue
Madison, WI 53704

COST: $24.00 (Looseleaf)

This book is probably the best resource presently available for the residential provider concerned with providing supportive living services to people with severe disabilities. It is made up of a series of six papers which describe Options in Community Living, a supported apartment program in Madison, Wisconsin.

The six sections of the manual include: 1) An overview of the Options program, with particular emphasis on the values which guide it and how it has changed over time; 2) A description of this agency's administrative structure, including the definitions of various administrators' roles, funding considerations, and consumer participation; 3) A review of Options' staff organization with clear descriptions of its team approach, various staff positions (including overviews of a typical day in the life of various staff members), and procedures for staff hiring, training, and evaluation; 4) An examination of the fundamental principles which guide this agency's service practice and a review of the processes used to plan, implement, and evaluate activities on behalf of each individual served by it; 5) A discussion of how an agency can aid someone's integration into the community with special attention given to major dilemmas, strategies, issues of relationship building, and advocacy for change in the community; and 6) An analysis of how services are adapted to meet the needs of "special populations," including people with physical disabilities, people with significant learning problems, and people with challenging behaviors. Each paper is supplemented with a variety of useful materials which run the gamut from maps and budgets to job descriptions, assessment forms, and policy statements.

The entire manual is useful, but the final three sections provide instructive thought provoking reading for anyone involved in supporting people with severe disabilities in the community. It is particularly refreshing to find a resource which directly recognizes the difficult issues of autonomy, choice, risk, and relationship building which emerge when an agency is truly committed to facilitating the integration of individuals into the community.

TITLE: A community-based system for the mental retarded: The ENCOR experience

AUTHOR: Casey, K.; McGee, J.; Stark, J.; & Menolascino, F.

PUBLICATION INFORMATION: 1985

University of Nebraska Press
901 North 17th Street
Lincoln, NE 68588-0520

This book uses the history of ENCOR to provide a training manual for planners, administrators, and human service professionals. It discusses in detail the practical information necessary for initiating, building, and maintaining community services. It also covers the philosophical and theoretical underpinnings of an enduring community-based program, practical ways to overcome difficult barriers, staff training approaches, parent involvement, and financial considerations.

TITLE: The right to a community environment

AUTHOR: Roesel, F. P. & Fanning, J. W.

PUBLICATION INFORMATION: 1979

The Residential Home for the
Mentally Retarded of Hamilton County, Inc.
3030 West Fork Road
Cincinnati, OH 45211

This is the proceedings of a conference on residential services; the 15 papers it contains provide a concise overview of many of the philosophical and programmatic issues which confront residential service providers, parents, and advocates. To a large extent the participant in this conference seems to avoid the trap of equating residential service with group homes. They discuss a number of apartment models, foster care, and family supports. Several presentations go out of their way to emphasize that everyone can and should receive services in the community--regardless of being called medically fragile or severely behavior disordered. The presentations fall into seven broad areas: 1) Staffing consideration, 2) Apartment living, 3) Parental dynamics, 4) Relation to institutions, 5) Accountability, 6) Community acceptance, and 7) Special issues for "hard to serve" people.

TITLE: Selecting, setting up, and surviving in an independent living situation: An inventory and instructional approach for handicapped individuals

AUTHOR: Vogelsberg, R. T., Anderson, J., Berger, P., Haselden, T. L., Mitwell, S., Schmidt, C., Skowron, A., Ulett, D., & Wilcox, B.

PUBLICATION INFORMATION: 1980

Center for Developmental Disabilities
499C Waterman Building
University of Vermont
Burlington, VT 05405

Essentially this document provides a number of comprehensive inventories for the many diverse considerations involved in developing an independent living situation. These lists should prove valuable to anyone trying to work through the nitty-gritty of establishing any kind of integrated community residential setting.

These materials provide a good place to start planning service. On initial perusal these checklists may appear to be almost too detailed. However, a moments consideration should make it clear that much of the minutiae covered here are elements which can have a profound effect on the ability of an individual with a severe physical limitation to live independently. Any potential user of the training model and the elements covered in the "surviving" module should review what is presented here with the need of a specific client in mind to determine which aspects of this material to use.

The inventories include: 1) Selecting a site: a) individual information, b) legal considerations, c) financial considerations, d) where to look, e) environmental considerations, f) architectural considerations, g) accessibility survey, h) landlord considerations, i) analyzing the site; 2) Setting up a site: a) initial preparations, b) material inventory,

c) acquisitions; and 3) Surviving in a site: a) schedules, b) expenses, c) training checklist, d) room specific skills, e) transportation, f) safety, g) leisure.

TITLE: A domestic training environment for students who are severely handicapped

AUTHOR: Freagon, S., Wheeler, J., Hill, L., Brankin, G., Costello, D., & Peters, W. M.

PUBLICATION INFORMATION: 1983

Journal of The Association for the Severely Handicapped 8(4), 49-61

This article describes a "domestic training environment" (community home) developed by an intermediate school district (ten rural public schools) to teach students with severe disabilities community living skills. The article describes the rationale for this program, logistics and cost issues, including administration, funding, and legal-safety issues, and instructional strategies. The authors describe the program's instructional objectives, provide sample routine checklists for domestic living and grocery shopping, and offer an example of a training schedule. Both special educators and residential service providers who work with people with severe disabilities will find useful ideas in this article.

TITLE: An alternative to the institution for young people with severely handicapping conditions in a rural community

AUTHOR: Singer, G. H. S., Close, D., Irvin, L. K., Gersten, T., & Sailor, W.

PUBLICATION INFORMATION: 1984

Journal of The Association for the Severely Handicapped 9(4), 251-261.

This article describes project SAIL (Systems Adaptation for Integrated Living) which uses fairly small (six person) group living situations to provide a short term (maximum stay three years) intensive training environment to prepare severely handicapped adolescents and pre-adolescents to move into a foster home or return to their natural home. It is noteworthy that the selection criteria for this program specifically defines school age individuals with severe or profound mental retardation, with other disabilities, little or no expressive language, and significant maladaptive behaviors--in other words some of the "hardest to serve" persons--as the people it will serve. The approach to staff development and the nature of the program are briefly described. The role of the "Community Liaison Specialist", whose job is specifically focused on facilitating community integration, seems to be a particularly significant innovation. Overall this program appears to be one viable approach to providing services to severely disabled persons with specialized needs in rural communities.

TITLE: Community living: A training home manual

AUTHOR: Singer, G. H. S.

PUBLICATION INFORMATION:

Oregon Research Institute
195 West 12th Avenue
Eugene, OR 97401

This manual addresses various aspects of developing community group homes for children and young adults with severe handicapping conditions. Based on experience with developing two group homes in rural California, the manual covers such issues as philosophy, administration, staffing, staff training, residents' daily schedules, instructional approaches, behavior management, and data systems. It also contains chapters on topics usually neglected in group home manuals, such as "Personalizing the Training Home" and "Social Support Networks." The manual is geared especially towards people with challenging behaviors. The appendices contain training exercises, sample policies and procedures, and other information. The manual is directed toward people on an agency level. Directors, boards, and group home managers will most find this manual useful.

TITLE: Manual: Neighborhood living project intensive tenant support model and specialized group home model

AUTHOR: Bellamy, G. T., Stern, A. J., Newton, S., Romer, M., Boles, S. M., Horner, R. H., & Tends, T.

PUBLICATION INFORMATION: 1984

Specialized Training Program
College of Education
University of Oregon
Eugene, OR 97403-1121

These two manuals describe the "Neighborhood Living Model" jointly developed by the University of Oregon's Specialized Training Program and the Washington Division of Developmental Disabilities. The manuals are nearly identical. The Intensive

Tenant Support Model is geared toward apartment living programs for up to six residents; the Specialized Group Home Model is geared to houses for five to eight residents (target size of five to six). The major difference between the manuals is that the Specialized Group Home Model manual covers external home maintenance, while the Intensive Tenant Support Model manual does not.

The manuals contain a complete set of policies and procedures for the operation of community residential settings. Both manuals contain a brief introduction describing the Neighborhood Living Model and four operations chapters. The first chapter, entitled "Management and Finance," covers staffing patterns, the role of governing boards, community relations, internal data systems, accounting procedures, and related issues. The second chapter deals with "Program Operations." This chapter, which is oriented toward people with severe disabilities, is probably the most useful and practical chapter in the manuals. The chapter covers Individualized Plan assessment, development, and implementation, coordination with other service providers, community training, task scheduling, community peer programs, and behavior management. The next chapter, "Apartment Operations" (House Operations), deals with mundane maintenance, cleaning, and repair aspects of the operation of community residential settings. The final chapter, "Health Care Maintenance," is devoted to nutrition, medications, emergency medical care procedures, records, and related issues. The Appendix of both which includes, among many other policies, a sound and sensible policy on Hepatitis B.

Many people will find these manuals useful. Whether or not they adopt the Neighborhood Living Model as a "package." State and regional officials, agency board members, and agency administrators will find many useful and practical policies, procedures, reporting forms and systems, and guidelines for establishing and operating community residential services in the manuals. The manuals would be especially helpful for new agencies. Since the manuals are so similar, it is not necessary to obtain both (we would recommend the Intensive Tenant Support Model, since this describes a model of service more in line with the "state of the art" in community living arrangements).

TITLE: Monitoring and maintaining quality community services

AUTHOR: Leismer, J.

PUBLICATION INFORMATION:

Available from Author
1060 Nokomis Way
Pontiac, MI 48054

This paper outlines 17 elements which the author feels are crucial to the development of high quality residential services. While by no means exhaustive these considerations provide a useful checklist for the analysis or planning of a regional service system: 1) normalized residential settings, 2) esthetically and programmatically appropriate settings, 3) selective screening of good administrators and providers, 4) adequate staff/client ratios, 5) coordinated service delivery, 6) individual program plans, 7) staff (with adequate training, pay, and benefits), 8) age-appropriate and need-appropriate day programs, 9) adequate funding, 10) rigorous standards for licensing, 11) natural family supports, 12) citizen advocacy, 13) supports for former clients living in the community, 14) small residences, 15) ample support services, 16) case management, and 17) adequate transportation.

TITLE: Planning and operating group homes for the handicapped

AUTHOR: Youngblood G. S. & Bensberg, G. J.

PUBLICATION INFORMATION: 1983

Texas Tech University
Rehabilitation Research and Training Center
in Mental Retardation

COST: $10.00

This text is directed toward service providers, advocacy groups, administrators and other interested parties who are given the task of setting up independent living facilities for developmentally disable people. It emphasizes the group home concept and discusses: determination of models for residential facilities, federal programs available, medicaid, intermediate care facilities, supplemental security income, Title XX, assessing the local housing market, funds for residential facilities, zoning, determination of population needs standards for accessibility, design considerations, home safety - life safety code, policies and procedures, client's rights, the Accreditation Council for Mentally Retarded and Other Developmentally Disabled Persons (AC MRDD), federal standards for intermediate care facilities for the mentally retarded (ICF/MR), case management, programmatic matters, and training program and resources. Appendices include an annotated bibliography, the Life Safety Code of the National Fire Protection Association, and a state agency directory.

TITLE: Systematic planning and programming for group homes and handbook for operators: An approach to accountability for group home operation: Working Paper No. 91

AUTHOR: Sitkei, E. G.

PUBLICATION INFORMATION: 1976

University of Oregon Rehabilitation Research and
Training Center in Mental Retardation

Includes two papers, one discussing systematic management systems applied to community residential facilities for the developmentally disabled, the other a handbook providing guidelines and techniques for designing and implementing an effective management system, including planning, budget, program development, goals and objectives and implementation. Includes tables, diagrams, and a programmed training model.

TITLE: Accounting system for group homes for developmentally disabled persons: Working Paper No. 97

AUTHOR: Snipe, H. W.

PUBLICATION INFORMATION: 1976

University of Oregon Rehabilitation Research and
Training Center in Mental Retardation

This handbooks is intended for managers of community based residential rehabilitation facilities with emphasis on the mechanics of accounting. Presents information required to allow managers to make decisions about types of accounting records to maintain for a group home. Includes a practices set, a practical application example, and a reporting manual, which contains the requirements for reporting financial information for purpose of the Group Home Cost Analysis Project. Includes forms and tables.

TITLE: Social change through integrated housing

AUTHOR: Falta, P. & Cayouette, G.

PUBLICATION INFORMATION: 1978

ERIC Document 155 878

Described is Project Normalization, a three-year demonstration project funded by the Canadian government to develop appropriate housing and supportive community services for severely physically disabled adults. Reviewed are the project's short term efforts to arrange for housing adaptation and community resources, as well as long term goals of policy changes ensuring integrated housing systems. Among other activities said to promote the integrated housing concept throughout Quebec and Canada are the establishment of a nonprofit corporation for housing, and the convening of a conference on accommodations and services. Also reported are results of a follow-up study of 23 severely disabled people in integrated housing.

TITLE: Independent living with attendant care:
1. A guide for the person with a disability
2. A guide for the personal care attendant
3. A message to parents of handicapped youth

AUTHOR: Board, M. A., Cole, J. A., Frieden, L., & Sperry, J. C.

PUBLICATION INFORMATION: 1980

Independent Living Research Utilization (ILRU)
The Institute for Rehabilitation & Research
1333 Moursand Avenue
Houston, TX 77030

COST: $3.50 per volume

A guide for the person with disability includes a discussion on where to look for a personal care attendant, how to word an advertisement, what to discuss when interviewing, how to establish a satisfactory working relationship, what are reasons for terminating an attendant, and how to develop a back up plan.

A guide for the personal care attendant addresses issues such as what independent living means and how attendant care supports it, good places to look for employment as an attendant, how to word a position wanted ad, issues that need to be clarified in interviewing, how to establish a satisfactory working relationship, and typical rewards to being a personal care attendant.

In A message to parents of handicapped youth, the issues discussed include what the independent living movement connotes for one's disabled child, how to teach responsibility to handicapped children, what support systems are necessary for living independently, which independent living situations require personal care attendants, and when to use attendants.

TITLE: The Macomb-Oakland Regional Center

AUTHOR: Provencal, G.

PUBLICATION INFORMATION: 1980

In T. Apolloni, J. Cappuccilli, & T. P. Cooke, (Eds.) Towards excellence: Achievement in residential services for persons with disabilities. Baltimore, MD: University Park Press

The first part of this paper briefly describes the development of the community residence system in Michigan's Macomb-Oakland region. The two basic models of service used in this region, group homes (average size seven persons) and community training homes (roughly analogous to foster care homes), are then described. While all this is interesting, the second part of the article, which outlines this region's model for residential staff training is even more useful. The development of the program is explained. The two major components of the program, the core curriculum and the continuing education classes, are described. This is followed by a discussion of the mandatory nature of the program, its cost, its strengths, and its weaknesses. The two appendices, which contain a question and answer session and the introduction to the training manual, supplement the reader's understanding of this regions approach to residential services.

TITLE: Residential services: Foster families

AUTHOR: Provencal, G.

PUBLICATION INFORMATION: 1976

In A national forum on residential services National Association for Retarded Citizens: Arlington, TX

This article describes how the Macomb-Oakland Regional Center transformed the traditional Foster care model for residential service into the Community Training Home Program. Specifically, the author recounts how the vehicles of funding, contracting, orientation, compulsory on-going training, case management, in-house programming, and monitoring are used to avoid some of the pitfalls often associated with foster care. The sections on recruitment and qualifications of foster parents are particularly complete and valuable.

At the very least, this article should stimulate the regional service planner to look for innovative ways of stretching the limits of existing models for service delivery.

TITLE: Community training home informational booklet

AUTHOR: Macomb-Oakland Regional Center

PUBLICATION INFORMATION:

Macomb-Oakland Regional Center
16200 Nineteen Mile Road
Mt. Clemens, MI 48044

This booklet is used to provide basic information to individuals who inquire about becoming foster care providers under this region's Community Training Home Program. It briefly describes: 1) Macomb-Oakland Regional Center, 2) the clients served, 3) the program, 4) necessary qualifications, 5) training, 6) consultative services, 7) the nature of in-home programming, 8) funding, 9) relationship with natural families, 10) responsibilities, and 11) steps in becoming a community training home. The appendices include fairly specific information on: facts about mental retardation, licensing regulations, the contractual agreement, and the provider training program. This resource provides a useful but bare-bones description of one important method for providing residential services. It also is a good example of the type of information which should be made available to individuals who express an interest in becoming service providers.

TITLE: ENCOR and beyond

AUTHOR: Hitzing, W.

PUBLICATION INFORMATION: 1980

In Apolloni, T., Cappuccilli, J., & Cooke, T. P. Towards excellence: Achievement in residential services for persons with disabilities. Baltimore, MD: University Park Press

In presenting an overview of the ENCOR system, the author offers some valuable insights into how to develop a system of community residential services and not just a group of residential facilities. A description of the organization of the regional service system is followed by a discussion of the "core-cluster" model for providing an individualized approach to residential services. Perhaps the key points made in this description are that A) no two of the residential options are identical and B) they are all indistinguishable from every other home in the communities in which they are situated. This author rejects the logic of a continuum of services in favor of providing "options" which are focused on the unique circumstances of specific individuals. Some of the other issues discussed are 1) staff/client ratio, 2) cost, 3) staff development, 4) the need to have a clear philosophy of services and not just a technology, and 5) the use of generic integrated community services.

TITLE: An apartment living plan to promote integration and normalization of mentally retarded adults

AUTHOR: Fritz, M., Wolfensberger, W., & Knowlton, M.

PUBLICATION INFORMATION: 1971

Canadian Association for the Mentally Retarded
Kinsmen NIMR Building
York University
4700 Keele Street
Downsview, Ontario M3J 1P3

This paper proposes that apartments are excellent sites for residential services for persons with mental retardation. Three apartment-based models are described: 1) apartment clusters, 2) co-residence and apartments, and 3) independent living apartments. The authors outline five advantages to these apartment living models: 1) flexibility, 2) a normalizing life style, 3) facilitates integration, 4) improved cost-benefit ratio, and 5) growth in the number of residential options available. An appendix provides fairly detailed guidelines concerning various administrative and programmatic issues.

While some aspects of this paper have become rather dated, most of the programmatic suggestions and all of the basic insights remain just as valued today as they were in 1971.

TITLE: Transitional teaching homes for individuals with developmental disabilities

AUTHOR: Glahn, T. J., Chock, P. N., & Mills, D. L.

PUBLICATION INFORMATION: 1984

Mental Retardation
22, 137-141

This article briefly describes the "Transitional teaching home model" as implemented in a small home-like setting in Camarillo, California. This model uses a group living situation (four persons) to prepare previously institutionalized persons with serious, "autistic/psychotic," behavior problems to move into foster home settings. A program of formal teaching which focuses on the problematic behaviors and "continuous" informal teaching to develop community living skills is managed by two teams of two "teaching parents." The average stay in the program is 15.4 months. At the time this article was written 79% of the graduates continued to reside in the foster homes to which they moved from the teaching home. A very brief description of this program's staff development process is also given.

We are somewhat troubled by the use of a "house parent" model in a setting like this where a number of the students have been young adults. But overall, within its few pages this article suggests one viable model to use in facilitating the movement of persons with very serious behavior problems into typical homes.

TITLE: On my own: The impact of semi-independent living programs for adults with mental retardation

AUTHOR: Halpern, A. S., Close, D. W., & Nelson, D. J.

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $15.95

This book presents an indepth study and analysis of the lives of approximately 300 adults with mental retardation who live in semi-independent living programs in four states (California, Colorado, Oregon, and Washington). By using both qualitative and quantitative research methods the authors try to capture and describe important trends in the development of independent and semi-independent living services for adults with mental retardation. The findings and perspectives of detailed interviews with clients and staff shows that the adjustment of adults with mental retardation to community life is quite good, with little evidence of serious problems or recidivism to more restrictive residential placements. The design of the study also includes a 6 to 8 months follow-up evaluation of clients and services programs; providing an opportunity for a more prospective analysis of adjustment.

"On my own" provides extensive information on one of the most recent additions to community-based residential alternatives for adults with mental retardation. It also analyzes past and present research findings, examines human services policy and management problems, and describes the perspectives of adults with mental retardation concerning living in their communities. In the final chapter, the authors propose an integrated systems model for improving research, service practices, policy information and evaluation of services outcomes.

Although this is basically an optimistic story, the book presents the many difficulties experienced by both clients and services providers. This book should be of particular interest to parents, professionals and others concerned with developing the full potential of citizens with mental retardation.

"On my own" explores its subject sensitively with both depth and breadth and leaves the reader with a clearer understanding of current practices and insights into ways of creating greater opportunities in society for citizens with mental retardation and other disabilities.

SERVICES: EDUCATIONAL

The materials in this section reflect an approach to the education of persons with severe handicaps which emphasizes functional curricula, community-based instruction, and full integration in neighborhood schools. These materials fall into three categories: 1) curriculum guides, 2) guides for integration, and 3) guides for planning and problem solving. One program description is also included.

TITLE: Severely handicapped students in regular schools: A progress report: Milwaukee public schools integration efforts

AUTHOR: Nietupski, J., Hamre-Nietupski, S., Schultz, G., & Ockwood, L.

PUBLICATION INFORMATION: 1980

Milwaukee Public Schools
Division of Exceptional Education and
Supportive Services
P.O. Drawer 10K
Milwaukee, WI 53201

COST: $5.00

This report provides a practical guide to the establishment and maintenance of integrated public school for students with moderate/severe special learning needs. The material is based on the authors' experience with integration efforts in the Milwaukee Public Schools during 1979 and 1980. Detailed accounts of building-level strategies and results along with concept or summary papers constitute the major body of the report. The appendices provide listings of media to be used in sensitizing students in regular education classes to the needs of students with special learning needs. Perhaps, the most impressive part of this report is found in the detailed accounts of classroom teachers concerning their experiences with integration. These are (or should be) required reading for teachers in training. Other audiences would find many fresh and exciting ideas in this report as well. This stands as yet another affirmation of the fact that students with (mild-profound) special learning needs can and do profit greatly from education in normative settings. The report also discusses the positive effects of such integration on typical students and their teachers as well.

TITLE: Longitudinal transition plans in programs for severely handicapped students

AUTHOR: Brown, L., Pumpian, I., Baumgart, D., Vandereuter, P., Ford, A., Nisbet, J., Schroeder, J., & Gruenewald, L.

PUBLICATION INFORMATION: 1981

Exceptional Children
47, 624-630

Authors argue that services for severely handicapped are of unacceptable quality because of untrained and undertrained personnel, segregated environments, education only in schools, curricula designed for children under five, lack of sufficient involvement by parents and guardians, programs which do not prepare students to function in nonschool and post school community environments. The article gives a brief overview of desegregated school models, including a curriculum model for adolescent and young adult severely handicapped students. In context of the four curricula domains of vocational, domestic, recreation/leisure and community functioning, the authors specify the critical components of individualized adaptations and transition plans. Individualized transition plans are 1) comprehensive; 2) individualized; 3) involve parents and guardians; 4) require participation of both sending and receiving personnel; 5) include related service personnel; 6) provide direct instruction in a variety of actual subsequent environments; and 7) are longitudinal in nature.

TITLE: Public school integration of severely handicapped students: Rational issues and progressive alternatives

AUTHOR: N. Certo, N. Haring, & R. York (Eds.)

PUBLICATION INFORMATION: 1984

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $19.95

As part of the literature on integration for severely disabled students, this book moves beyond the almost repetitive debate of integration/segregation: It makes an important contribution by illuminating and extending our understanding of the topic of integrating severely disabled learners. It enriches our knowledge of how schools can foster integration by describing basic principles around which curricula and administrative practices can be designed.

The specific chapters examine: the issues and alternatives for statewide integration, the complex nature of real integration, the parent perspective on obtaining integrated services, school administrative policies which foster integration, how to develop shared goals, principles and instruments for measuring a school's resolve for integration, teacher preparation and integration, and the meaning of integration. In addition, five chapters provide guidelines for developing curricula which is geared to facilitating integration in the areas of social performance, peer interaction, social behavior, interpersonal interactions, and recreation and leisure.

TITLE: Integral involvement of severely handicapped students within regular public schools

AUTHOR: Hamre-Nietupski, S. & Nietupski, J.

PUBLICATION INFORMATION: 1981

Journal of The Association for the Severely Handicapped **6**(2), 30-39.

The authors focus upon a number of formal and informal methods which would insure a less restrictive environment for severely handicapped students. The argument is that integration should go beyond physical integration to a combination of methods on a longitudinal basis. Formal/informal methods for faculty can include (a) designation of a consultant for integration, (b) present inservice, (c) class visits, (d) assuring the severely handicapped students use as many school facilities as possible. There are about twenty-two suggestions for staff and six for students to help foster integral involvement.

TITLE: Towards the realization of the least restrictive educational environments for severely handicapped students

AUTHOR: Brown, L., Wilcox, B., Sontag, E., Vincent, B., Dodd, N., & Gruenewald, L.

PUBLICATION INFORMATION: 1977

Journal of The Association for the Severely Handicapped **2**(4), 195-201

The authors argue that least restrictive environment means desegregation. The basic argument is that service delivery models for the severely handicapped should closely approximate the best models used for non-handicapped students. There are a number of dimensions in an integrated education for the severely handicapped: (1) educational experience should be representative and prepare the severely handicapped to function in an integrated environment; (2) the ratio between severely handicapped and nonhandicapped students should represent less than 2% of the population at any chronological age; (3) there should be chronological age appropriate educational environments; (4) environments and architecture should be adapted; (5) there should be a functional curriculum; (6) the organization of the school day should approximate that of nonhandicapped peers; (7) there should be equal access to school facilities and resources; (8) transportation time should approximate time and type used by nonhandicapped peers; (9) necessary supportive services should be available.

TITLE: The teaching research curriculum for moderately and severely handicapped

AUTHOR: Fredericks, H. D. (Ed.)

PUBLICATION INFORMATION: 1980

Charles Thomas
301-327 East Lawrence Avenue
Springfield, IL 62703

In the early 1970's Teaching Research in Monmouth, Oregon was one of the first organizations to accept the challenge of developing systematic curricula and training qualified teachers for students with severe disabilities. These two volumes culminate 10 years of experience in these areas, and should provide the field with a well-planned carefully calibrated plan for meeting the developmental needs of many children with moderate to severe disabilities. The curriculum itself is based on a behavioral orientation toward teaching and learning. It includes a wealth of task analyses and specific instructions for placement testing and "branching" (the process by which one extends, or breaks down specific objectives into smaller parts). Teachers and instructional programs should find the curriculum extremely helpful in designing programs for students with disabilities, although caution should be exercised in simply regarding the task analyses as "cookbook" solutions to the many and varied problems of individual learners. The Gross and Fine Motor Section covers skills such a head control, sitting, standing, and walking as well as grasping, reaching, hand control, and visual-motor coordination. The Self-Help and Cognitive Sections cover skills such as eating, dressing, and personal hygiene as well as personal information, pre-reading, and reading, writing, and number of concepts. Given the current emphasis on the development of functional community-oriented life skills in adolescents with severe disabilities, some readers might question the relevance of this curriculum to the needs of older students. However, it provides an outstanding base for planning.

TITLE: Implementing a community-based educational model for moderately/severely handicapped students: Common problems and suggested solutions.

AUTHOR: Hamre-Nietupski, S., Nietupski, J., Bates, P., & Maurer, S.

PUBLICATION INFORMATION: 1982

Journal of The Association for the Severely Handicapped
7(4), 38-43

A common administrative reaction to proposals to adopt a community based training model for severely handicapped students is that, while this is a good idea on paper, the relatives of implementing such a model prohibit school districts from adopting it. This article outlines six commonly cited barriers to community-based instruction: 1) limited staff, 2)transportation, 3) scheduling, 4) cost, 5) negative reaction to curriculum emphasis change, and 6) applicability to multiply handicapped students. For each of these common objections the authors offer a number of solutions drawn from the experience of implementing a community-based instructional model in 10 school districts in the state of Iowa.

TITLE: Severely handicapped students: An instructional design

AUTHOR: Sailor, W. & Guess, D.

PUBLICATION INFORMATION: 1983

Houghton Mifflin Company
Boston, MA

COST: $25.45

The purpose of this book is to provide teachers, therapists, and other professionals serving severely disabled students, with an organizational framework from which to design educational programs. The authors have combined a precise, behavioral approach to instruction with curricular decision making that is based on cognitive theory as well as environmental demands.

The book is divided into 12 chapters, beginning with an overview of recent legal and legislative actions that support the right of severely disabled individuals to receive educational services in the least restrictive setting. This overview is followed by two chapters which provide a technical analysis of how motivation and stimulus control contribute to the learning process. Subsequent chapters serve to broaden the perspective by describing curriculum strategies that are consistent with preparing severely disabled students to function in integrated community environments. Individual chapters are devoted to curriculum approaches for infants and preschool children, elementary school children, and secondary-level students. A final chapter is devoted to descriptions of support systems for adults. Throughout, the text uses illustrations and examples to convey how the approaches might be applied to students with severe multiple disabilities.

TITLE: Design of high school programs for severely handicapped students

AUTHOR: Wilcox, B. & Bellamy, G. T.

PUBLICATION INFORMATION: 1982

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $15.95

Wilcox and Bellamy, who have had extensive experience in developing programming for school-aged individuals and adults with severe handicaps, have combined their unique perspectives in this book which focuses on strategies for preparing high school students for the adult world. A comprehensive model of secondary services is described which is based on current principles and practices such as chronological age-appropriateness, integration, community-referenced instruction, and transitional services.

The book is divided into 13 chapters which address curriculum planning, classroom operation, instructional methodology, transitional planning, and program administration. An entire chapter is devoted to each of the following programmatic areas: vocational; leisure and recreational; and independent living. Many of the chapters contain useful examples of skill listings, evaluation checklists, IEP objectives, and schedules. Although this book is intended for teachers working with secondary-aged students, it can also serve as a valuable resource for teachers at the elementary school level. Teachers of students with severe multiple disabilities, however, may find that the book does not provide enough examples of how the information might apply to their students.

TITLE: Teaching autistic children: A functional curriculum approach

AUTHOR: Neel, R. S., Billingsley, F. F., McCarthy, F., Symonds, F., Lambert, C., Lewis-Smith, N., & Hanashiro, R.

PUBLICATION INFORMATION: 1983

College of Education
Project IMPACT
Experimental Education Unit WJ-10
University of Washington
Seattle, WA 98195

This volume is a curriculum package which represents a comprehensive application of principles involved in instructional planning and service delivery which is referenced to the criterion of ultimate functioning. Each of the components (assessment, decision-making, and instructional planning/implementation) was field-tested in various public school programs in the Seattle area. A particularly useful item in the manual is the home-school inventory process and form, which the teacher and parents complete independently and then use to reach mutual agreement on IEP goals which are based upon maximum functionality of perceived need areas. The manual also includes all needed procedures to assess the student's present level of functioning on daily routines--including adaptations needed for individual component skills--and deliver instruction in the context of actual, activity routines as they occur in current and future environments. The curriculum has been replicated in various school districts outside the state of Washington, including schools in such diverse areas as Alaska and Minnesota.

SERVICES: VOCATIONAL

The materials in this section reflect the fact that in most sections of the country the vocational or day programs for severely handicapped individuals are woefully inadequate. To a large extent this service sector is only beginning to explore the possibilities for meaningful integrated vocational opportunities for people with severe disabilities. This situation is seen in the fact that none of these resources adequately describe a full range of vocational services for the people on whom this project is focused. What these resources do offer, however, is some solid guidelines for the development of innovative vocational programs for the most severely disabled individuals.

TITLE: Establishing and maintaining vocational training sites for moderately and severely handicapped students: Strategies for community/vocational trainers.

AUTHOR: Nietupski, J. A., Hamre-Nietupski, S., Welch, J., & Anderson, R. J.

PUBLICATION INFORMATION: 1983

Education and Training of the Mentally Retarded 18, 169-175.

Several strategies are presented which might be employed by community/vocational trainers in establishing and maintaining community-based vocational training sites. The strategies include both recommended procedural steps as well as interpersonal approaches employed by successful community/vocational trainers.

TITLE: Implementing a community-based vocational training model: A process for systems change

AUTHOR: Wershing, A., Gaylord-Ross, C., & Gaylord-Ross, R.

PUBLICATION INFORMATION: 1986

Education and Training of the Mentally Retarded 21, 130-137.

This article describes procedures necessary to implement a community-based instructional model for vocational training. Issues involved in facilitating systems change are addressed. Strategies for use in gaining administrative support, in programming, community site selection and development, parent involvement, and employer participation are provided. Benefits of community-based vocational training for disabled youth in preparation for transition to employment opportunities are illustrated through presentation of a case study.

TITLE: Assisting persons with severe disabilities to achieve success in integrated work places: Critical Elements

AUTHOR: Nisbet, J. & Callahan, M.

PUBLICATION INFORMATION: In Press (To be published Spring 1987)

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.) Community integration for people with severe disabilities. Teachers College Press, 1234 Amsterdam Avenue, New York, NY, 10027.

This chapter provides an overview of the elements of successful job placements for people with severe disabilities. Specifically the authors outline the rationale for a fully individualized approach to job placement, methods for coordinating services across the various agencies which are usually involved in the life of a person with a severe disability, and key issues related to supports and skill development with special emphasis given to natural supports and the development of on the job relationships.

TITLE: Four supported employment alternatives

AUTHOR: Mank, D. M., Rhodes, L. E., & Bellamy, G. T.

PUBLICATION INFORMATION: 1986

In W. Kiernan & J. Stark (Eds.), Pathways to Employment for Adults with Developmental Disabilities.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624.

COST: $35.95

This chapter compares four models of supported employment (i.e., the supported jobs model, the enclave model, the mobile crew model, and the benchwork model) on a number of variables including integration, wages, and success in serving people with severe disabilities. There are a number of issues with the comparisons (e.g., both the supported jobs model and the enclave models are rated as high on integration when there appears to be substantial differences on this variable between the two models), but the article provides a good starting point for discussion on supported employment approaches.

TITLE: The supported work model of competitive employment for citizens with severe handicaps: A guide for job trainers

AUTHOR: S. Moon, P. Goodall, M. Barcus, & V. Brooke (Eds.)

PUBLICATION INFORMATION: 1985

Rehabilitation Research and Training Center
School of Education
Virginia Commonwealth University
1314 West Main Street
Richmond, VA 23284-0001

COST: $9.00

This manual gives practical information on implementing a supported work approach to individual employment in business and industry. Written for people who are directly involved in job placement and training, the manual addresses job development, job placement, job site training and follow-up. Also included are sample forms, a resource guide and a glossary.

The manual is one of the few resources available to direct service staff that describes in a step-by-step way individual job placement and training using a supported work approach. The supported work model described in this manual (1) enables people with disabilities to work at job sites in business and industry before they meet traditional requirements for "job readiness", (2) involves long-term assessment and follow up services, and (3) provides intensive training at the work site. The manual is must reading for people who are involved in the development and implementation of supported work. People who are interested in issues such as job modifications or working with people with "challenging behaviors" at the work site will need to supplement the manual with other resource materials. Overall, an excellent resource.

TITLE: Establishing effective community-based training stations

AUTHOR: Stainback, W., Stainback, S., Nietupski, J., & Hamre-Nietupski. S.

PUBLICATION INFORMATION: 1986

In F. Rusch (Ed.), Competitive Employment Issues and Strategies.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, Maryland 21285-0624

COST: $34.95

This chapter describes a rationale for the use of community-based training sites during the school years and suggests guidelines for developing and maintaining these sites. The chapter is aimed primarily at school personnel who are unfamiliar with the use of community-based training sites.

TITLE: Impact of federal programs on the employment of mentally retarded people

AUTHOR: Conley, R. W.

PUBLICATION INFORMATION: 1985

In K. C. Lakin & R. H. Bruininks (Eds.) Strategies for achieving community integration for developmentally disabled citizens. Baltimore: Paul H. Brookes Publishing Co.

This article examines the various ways in which a variety of federal programs affect the employment of people with a disability. One problem, which the authors highlight, is the tacit assumption in most federal programs that people with mental retardation can be neatly divided into groups which either can or cannot be gainfully employed. As a result, most of these programs contain substantial disincentives for the employment of many disabled people. Numerous specific examples are made for reordering priorities in mental retardation services.

TITLE: Integrated work opportunities for adults with severe handicaps: The extended training option

AUTHOR: Brown, L., Shiraga, B., York, J., Kessler, K., Strohm, B., Rogan, P., Sweet, M., Zanella, K., VanDeventer, P., & Loomis, R.

PUBLICATION INFORMATION: 1984

Journal of The Association for the Severely Handicapped 9(4), 262-269.

This article takes the position that one major reason why those adults with the most severe intellectual handicaps are prevented from performing meaningful work in nonsheltered environments is the requirement that they cannot do so unless they receive direct pay. Unfortunately, as long as direct pay is an admission requirement to the real world of work, confinement to unnecessarily costly, antihabilitative, and counter productive segregated facilities and prevocational programs that never lead to real work will prevail. The highly selective and closely monitored use of an Extended Training Option is offered as a reasonable procedure that can be used to arrange for nonsheltered functioning while the attitudes and skills necessary for direct pay are developed. Specifically, workers with severe intellectual handicaps should be placed in nonsheltered vocational environments, unless health considerations are contraindicated. Then they should be taught to perform meaningful work. All reasonable attempts to secure contingent direct pay should be made. Direct pay can no longer function as a barrier to integrated work opportunities.

TITLE: Quality and equality in employment services for adults with severe disabilities

AUTHOR: Bellamy, G. T., Rhodes, L. E., Wilcox, B., Albin, J. M., Mank, D. M., Boles, S. M., & Horner, R. H.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps
9(4), 270-277

This article responds to Brown, et. al.'s paper in the same issue of this journal. While they agree with Brown et. al. about the capability of persons with disabilities, the importance of integration, and the failings of typical services, the authors of this article believe that the extended training proposal represents an unnecessary retreat from values that have guided development of exemplary school and community services for persons with severe handicaps. As an extended outcome of services, the proposed program needlessly sacrifices wages and other employment benefits, distorts the benefits of integration by looking only at the work place, and tolerates unequal treatment of citizens with severe handicaps. Relying on unpaid work as a strategy for time-limited employment preparation creates the risk of over use and of perpetual readiness programming. This article suggests that professional effort could be better spent in developing supported employment opportunities. Current federally supported employment initiatives are discussed as providing a framework for combining wages and integration and offering support for local program development.

TITLE: Try another way training manual

AUTHOR: Gold, M.

PUBLICATION INFORMATION: 1980

Research Press
2612 North Mattis Avenue
Champaign, IL 61820

COST: $8.95

This manual describes the philosophy and procedures of Try Another Way, an approach for teaching moderately, severely and profoundly mentally retarded persons and developmentally disabled persons who are difficult to train. An alternative definition of retardation is proposed which stresses level of functioning determined by the availability of training technology. Try Another Way is explained as the use of task analysis to teach manual tasks to disabled persons.

The manual covers the following aspects of the approach: task analysis (explanation and an example of teaching a complex assembly task to retarded blind persons); rules for training and reinforcement; a discussion of the concept of influence; and an interview with M. Gold in which he emphasizes the need for systematic training rather than diagnosis. Four training projects and their task analyses are presented (shaking hands, building pallets, washing hands, and folding napkins). The remainder of the manual provides information on publications, films, and training services.

TITLE: Vocational habilitation: A time for change

AUTHOR: Pomerantz, D. J., & Marholin, D.

PUBLICATION INFORMATION: 1977

In E. Sontag, J. Smith, & N. Certo (Eds.) Educational Programming for the Severely and Profoundly Handicapped. Reston, VA: Council for Exceptional Children.

This is one of the few published works that addresses policy and service delivery issues in vocational programs for people with severe disabilities. The authors describe the problems of traditional vocational service models, outline a list of principles for alternative models, and present future directions for vocational habilitation.

TITLE: "Did I say that. . ." Articles and commentary on the try another system.

AUTHOR: Gold, M.

PUBLICATION INFORMATION: 1980

Research Press
2612 North Mattis Avenue
Champaign, IL 61820

COST: $18.95

The book contains 27 papers on the Try Another Way System, a program designed to teach manual tasks to people labeled moderately, severely, and profoundly retarded. Entries include the following: "The Try Another Way System in Perspective;" "Preworkshop Skills for the Trainable: A Sequential Technique;" "The Interdisciplinary Approach: A Nominal Fallacy;" "The Preparation of Secondary Teachers of the Mentally Retarded;" "Discrimination Learning;" "Adolescents on a Complex Task: Acquisition, Transfer, Retention;" "Research on the Vocational Habilitation of the Retarded: The Present, The Future;" "Adaptive Behavior Philosophy: Who Needs It;" "The Learning of Difficult Visual Discriminations by the Moderately and Severely Retarded;" "The Effects of Verbal Labels on the Acquisition and Retention of a Complex Assembly Task;" "Factors Affecting

Production by the Retarded: Base Rate;" "Redundant Cue Removal Skill Training for the Retarded;" "An End to the Concept of Mental Retardation: Oh, What a Beautiful Mourning;" "An Alternative Definition of Mental Retardation;" "Macron, Inc.: A Request for a Program Related Investment;" "Vocational Training;" "Work Skill Development;" "Some Thoughts on Training;" "Vocational Training for the Mentally Retarded;" "Five-Year Retention of an Assembly Task by the Moderately and Severely Retarded;" "Task Analysis of a Complex Assembly Task by the Retarded Blind;" "Task Analysis for Teaching 8 Practical Signs to Deaf-Blind Individuals;" "Removing Some of the Limitations of Mentally Retarded Workers by Improving Job Design;" "Mealtime;" "Issues in Prevocational Training;" and "Behind the Wheel Training and Individuals Labeled Moderately Retarded."

TITLE: Community programs for severely handicapped adults: An analysis

AUTHOR: Bellamy, G. T., Sheehan, M. R., Horner, R. H., & Boles, S. M.

PUBLICATION INFORMATION: 1980

Journal of The Association for the Severely Handicapped 5(4), 307-324.

This paper examines the situation of severely handicapped individuals who are classified as not ready for vocational training and so have generally been excluded from both sheltered workshops and real work opportunities. These individuals are served in "Adult Day Programs." This article raises serious concerns about these programs based on a) the lack of real work opportunities, b) disincentives to providing work opportunities, c) the fragmentation and inertia that results from current funding and regulations, and d) the unavailability of services to many persons with severe disabilities. A number of suggestions are made for overhauling this system in order to overcome these limitations and provide real vocational opportunities to persons with severe disabilities.

TITLE: Competitive employment: New horizons for severely disabled individuals

AUTHOR: Wehman, P.

PUBLICATION INFORMATION: 1981

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $17.95

This book is about designing and implementing vocational programs that result in placing clients in nonsheltered competitive work environments. The primary focus is on those severely disabled individuals who have traditionally been under served or excluded from rehabilitation or vocational education services. A systematic approach to accomplishing this goal of real work opportunities is based on an ecological approach to assessing employability. The topics discussed include 1) training for competitive employment, 2) placement, 3) job retention, 4) public perceptions, 5) developing non-vocational skills, 6) evaluating failures. Seven model programs are described. An appendix contains an annotated bibliography on the employability of disabled persons.

SERVICES: RESPITE AND OTHER FAMILY SUPPORTS

It is generally accepted with little or no debate that a) all children are best off being raised within a family and b) the needs of severely handicapped children are best met in a family (natural, adoptive, or foster) home. Unfortunately the service system has traditionally been more adept at prematurely cutting familial ties than at strengthening them and helping them to endure. The resources in this section attempt to offer some suggestions for services which may help overcome this systemic disregard for human relationships.

TITLE: Designing programs to support family care for persons with developmental disabilities: Concepts to practice

AUTHOR: Agosta, J., Bradley, V., Rugg, A., Spence, R. and Covert, S.

PUBLICATION INFORMATION: 1985

Human Services Research Institute
120 Milk Street, Eighth Floor
Boston, MA 02109

COST: $12.00

This report on family support services highlights the trends in the literature, presents the results of a 50 state survey (with case studies of six of the states), and includes information on the development of a family support policy in Virginia. Six key issues surrounding the development of family support services are discussed including the role of the family, program eligibility, service administration, permissible services, use of existing resources and facilities and program evaluation.

The report is written primarily for professionals and service planners who are interested in the status of family support service programs in this country and in the major issues involved in their development.

TITLE: Family care for persons with developmental disabilities: A growing commitment

AUTHOR: Agosta, J. M. & Bradley, V. J. (Eds.)

PUBLICATION INFORMATION: 1985

Human Services Research Institute
Family Care Report
120 Milk Street, Eighth Floor
Boston, MA 02109

COST: $19.00

The report includes five concept papers on family support issues, including a parental perspective, the perspective of a person with a disability, an overview of the goals and purposes of family support services, a review of current options for family support policy, and a future policy directions statement. The appendices include a directory of 22 statewide family support initiatives and 11 organizations that offer parents financial planning services.

Families will find select chapters in the report useful. Overall, the resource is focused primarily on the planners, policy analysts and other professionals.

TITLE: State family support/cost subsidy programs

AUTHOR: Bates, M. V.

PUBLICATION INFORMATION: 1985

Madison, WI: Wisconsin Council on Developmental Disabilities

This is a summary of family support and/or subsidy programs throughout the United States. It includes a state-by-state description of 24 state programs which gives information on program type, goals and objectives, appropriations, number of people served, administering agency, eligibility, priority services, subsidy/supplemental payments information, method of implementation, and approach to evaluation.

TITLE: Developing respite care services for families of handicapped persons

AUTHOR: Salisbury, C., & Griggs, P. A.

PUBLICATION INFORMATION: 1983

Journal of The Association for the Severely Handicapped 8(1), 50-57.

This article provides the system planner with an overview of the issues surrounding the provision of respite care. Particular emphasis is given to pointing out the need which respite care fills, the cost of this service, liability, where respite can be provided, and who is a possible service provider. The following are identified as the principle components of a system of respite services: information, recruitment, training, coordination, and the development of an on-going support system. Generally this article provides some valuable information and ideas, but the authors inclusion of settings such as institutions and regional centers as possible sites for respite services does not seem to be in line with the intent of this service to support persons and families in their natural communities.

TITLE: Respite care: Principles, programs, and policies

AUTHOR: Cohen, S., & Warren, R. D.

PUBLICATION INFORMATION: 1985

Pro ED
5341 Industrial Oak Boulevard
Austin, TX 78735

COST: $18.00

This book provides a comprehensive coverage of all aspects of respite care. As such, it addresses why respite care is needed, what functions it serves, and what research has to tell us about respite care. Effective models of respite care are given. Also covered are the selection and training of respite care workers, legal and fiscal perspectives, how to start and operate a respite care program, issues and problems, and respite care for families of the elderly, the terminally ill, and other dependent populations.

The contents of this book include: 1) families in need, 2) respite care as a family support service, 3) what research tells us about respite care, 4) respite care programs in action, 5) legal and fiscal perspectives, 6) respite care workers, 7) respite care as a generic service, and 8) issues, corollaries, prospects, and conclusions.

TITLE: Respite care provider training: Current practices and directions for research

AUTHOR: Salisbury, C. L.

PUBLICATION INFORMATION: 1984

Education and Training of the Mentally Retarded
19, 210-215

This article offers some valuable suggestions for meeting the training needs of respite care providers. It criticizes most existing approaches to training for failing to address the real needs as they are perceived by the people who are actually providing respite services. Nine elements are suggested as important in designing and implementing a field based training program which is responsive to the needs of service providers.

TITLE: Handicapped infants and children: A handbook for parents and professionals

AUTHOR: Tingey-Michaelis, C.

PUBLICATION INFORMATION: 1983

Pro ED
5341 Industrial Oak Boulevard
Austin, TX 78735

COST: $14.00

This book provides parents and professionals with practical information on how to meet the needs of the handicapped child with the least disruption to family life. It describes how family attitudes and resources can be organized to meet the special and day-to-day developmental needs of the handicapped child. Stressing the importance of balancing extra care and attention for the handicapped child with the child's need for usual childhood experiences, the book's topics are centered around the home and neighborhood. It provides many practical suggestions to help parents organize daily routines and family and neighborhood interaction, as well as suggestions for collaboration and cooperation to obtain the necessary medical, educational, and public services required by the handicapped child and the family.

TITLE: Availability and accessibility of family support services

AUTHOR: Castellani, P. J., Downey, N. A., Tausig, M. B., & Bird, W. A.

PUBLICATION INFORMATION: 1986

Mental Retardation
24(2), 71-79.

Results of a study of nine family support services delivered by a sample of 133 public and private agencies in New York State were reported. Factors affecting the availability and accessibility of these services statewide were examined. Problems of service identification and definition and variations in the location, type, auspice, size, and structure of service agencies were shown to affect the availability and accessibility of family support service statewide. The provision of family support services as groups of services was shown, and the impact of a lack of separate budgeting and existing eligibility criteria for these services were described. Implications for design and implementation of family support services programs were discussed.

TITLE: Family Support Project: Final report for the period of January 1, 1979 through September 30, 1979

AUTHOR: D. Frisbie, & K. Slater (Eds.)

PUBLICATION INFORMATION: 1979

ERIC document 219 919

The Family Support Project in Lansing, Michigan, provides a variety of family support services to help maintain severely mentally and severely multiply impaired children in their own communities, and whenever possible, in their own homes. Services offered include case management, family therapy, respite services, special needs purchases, administration, program evaluation, and a parent task force serving in an advisory capacity to project staff. Among results from nine months of operation are: efforts to outreach families with children residing in state institutions were hindered by confidentiality and release of information regulations; the most highly used services were those of local schools; and three basic need areas expressed by families were parent to parent support as early as possible, specialized training opportunities for family and staff who care for children, and additional short and long term community residential alternatives. Other findings related to project goals are that the proportion of families maintaining their children in the community or in their own homes was not increased; eligible families received a number of support services not previously available to them; and the levels of intervention and assistance to individual families were not reduced. Among recommendations were that an official emergency respite service system be established as part of an agency wide on-call system in response to participant needs for special assistance on a 24 hour basis. Appended are an outline on national family programs and services, a table comparing family subsidy/support programs in selected states, a fee schedule, a list of special needs purchases, a copy of the "Quality of Life Questionnaire" administered to families, a satisfaction questionnaire, and a summary of previous project issue.

TITLE: Family care of developmentally disabled members: Conference proceedings

AUTHOR: Bruininks, R. H., & Krantz, G. C.

PUBLICATION INFORMATION: 1979

Information and Technical Assistance Project
in Deinstitutionalization
207 Pattee Hall
150 Pillsbury Drive, S. E.
University of Minnesota
Minneapolis, MN 55455

COST: $3.00

These proceedings address the significant social, economic, and programmatic issues involved in providing natural and surrogate family "care" to developmentally disabled persons. There is wide variability in the articles presented in this volume. They range from highly theoretical discussions of sociological and economic models of the factors which influence family care to practical descriptions of needs, services, and specific schemes for financial support (e.g., vouchers, direct cash subsidies). Two chapters summarize 1) the plenary sessions and 2) small group analyses of the need for a coherent public policy which supports the family. Two appendices contain: a) a list of 21 family support projects from various locales with brief descriptions and b) an annotated bibliography on family care of developmentally disabled members.

TITLE: An evaluation of home-based respite care

AUTHOR: Upshur, C. C.

PUBLICATION INFORMATION: 1982

Mental Retardation
20, 58-62

An earlier study of in home respite care found that a number of factors made it impossible for the families of severely and profoundly mentally retarded and multiply handicapped persons to use the service. This article reports on a pilot project which sought to rectify these problems. The service agency was more selective in recruiting providers, paid these providers a higher stipend, set up an emergency on call backup system, and required the providers to attend 60 hours of training (for which they were paid). Four case histories are given to document the serious nature of the disabilities of the persons served under this project and the difficult problems which the providers faced. A follow-up study found that the families who used the service were highly pleased with the service and the providers found the required training to be useful. The article contains a number of practical suggestions for setting up this type of service and points out that this method for providing respite services is particularly cost efficient.

TITLE: In home respite care program development: Background, coordinators manual, training manual

AUTHOR: Parham, J. D., Hart, T., Terraciano, T., & Newton, P.

PUBLICATION INFORMATION:

Research and Training Center in Mental Retardation
Box 4510
Texas Tech University
Lubbock, TX 79409

COST: $15.00

This manual attempts under one cover to provide a comprehensive resource for the development and administration of an in-home respite service for families with a developmentally disabled member. More properly the model described is respite care in-a-home, either the consumer's home or the provider's family home. The first unit provides background information: need for respite service; models of service; program variables; planning and funding; and organizing a core planning group. The Appendices to this unit cover: A) law, B) planning and evaluation, C) resources for grants, D) outline of an effective meeting, E) a needs assessment survey, F) cost and budgeting, G) job description and interviewing for a program coordinator. Unit II is the program coordinator manual. This unit discusses: resource evaluation, program philosophy, time guidelines, planning committees, group presentations, establishing a communications system, fees, legal issues, recruiting providers, recruiting consumers, matching consumers and providers, program administration, and follow-up. The final unit outlines the training of respite care providers. This includes general guidelines, handouts, exercises, training goals, planning training sessions, and observational guidelines. The actual training sessions include these topics: introduction and overview of developmental disabilities, three provider-consumer interview exercises, first aid and CPR, seizure information, medication information, behavior modification, administrative information, and competency assessment.

This is a solid nuts and bolts how to do it approach to setting up a service.

TITLE: Respite care: Support for persons with developmental disabilities and their families

AUTHOR: Salisbury, C. L., & Intagliata, J. (Eds.)

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $23.95

This book represents state-of-the-art knowledge on respite care. It is an effort to respond to the growing need for information on respite care and family support services. It is intended to enable the readers to understand more clearly the specific needs that these services are trying to address, the variety of programs available and provide the readers with a perspective on the rationale for, and design and evaluation of respite care programs. In an effort to present the broadest and most useful perspectives on respite care, the editors purposefully solicited a collection of authors who represent a wide variety of relevant viewpoints on respite services. Included are those of program developers and implementors, policymakers, researchers, and parents of individuals with developmental disabilities.

The book is divided into three major sections:

1) Rationale and need for respite services.

2) Issues and models for delivering respite services.

3) Evaluation of respite services.

The editors have chosen to restrict the content to respite services for children with developmental disabilities and their families. Anyone involved in or interested in respite care for this group will benefit from reading this book. Because many of the generic features of the processes and information contained in the book transcend populations, individuals working with groups other than persons with developmental disabilities may also find this a useful text.

This book departs from many previous texts on respite care in that it places the design, development and evaluation of respite services within the broader context of the theory and research on family stress, adaptation and coping.

OTHER SERVICES

Numerous services are outlined, in the section on planning a comprehensive service system, as being essential for supporting severely handicapped persons in their communities. For this section we reviewed some resources which examine a few of those services a bit more thoroughly. The services examined are: 1) case management, 2) guardianship, and 3) early childhood special education.

TITLE: Moving persons with developmental disabilities toward less restrictive environments through case management

AUTHOR: Wray, L. & Wieck, C.

PUBLICATION INFORMATION: 1985

In K. C. Lakin & R. H. Bruininks (Eds.) Strategies for achieving community integration for developmentally disabled citizens. Baltimore: Paul H. Brookes Publishing Co., pp. 219-230.

The authors take the position that effective case management is "the glue which holds together" a community-based services system. They see this role as supporting natural networks, providing for flexibility, effecting true individualization, offering real choices, and enforcing cost-efficiency. They further suggest that only by exploring the potential of the case manager can dollars actually be brought to follow individuals rather than programs. Various definitions of case management are explored. The elements which are identified as central to effective service are a well-defined process, clear-cut responsibilities, good information about clients and services, inter-agency agreements, and adequate resources.

TITLE: Case management in long-term care programs

AUTHOR: Simpson, D. F.

PUBLICATION INFORMATION: 1982

Center for the Study of Social Policy
236 Massachusetts Avenue, N. E.
Suite 405
Washington, DC 20002

COST: $5.00

This report is a valuable resource for anyone attempting to understand or define the role of the human service case manager. This report provides an overview of how case management has been defined as a necessary service in response to the increasing complexity of a community-based service system. The diverse roles (from client advocate to service coordinator to cost containment officer) which have been assigned to the case manager are outlined. Twelve (12) federal projects, which defined the case management role in different ways, are discussed in detail with emphasis on the strengths and weakness of the particular model of management utilized in each instance.

TITLE: A new look at guardianship: Protective services that support personalized living

AUTHOR: T. Appolloni & T. P. Cooke (Eds.)

PUBLICATION INFORMATION: 1984

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $24.95

The book was written to acquaint parents and professionals with emerging options for improving the security, stability, and continuity of services for dependent persons. The contents of the book are organized into two sections. The first includes chapters that convey general knowledge and opinions about the area of guardianship. The various chapters provide overviews of 1) human services trends affecting guardianship, 2) recent developments in guardianship law, 3) a parent's perspective on the importance of guardianship services, 4) a counseling psychologist's perspective, 5) research on the determination of personal competence, and 6) questions parents must answer when making long term plans for their disabled child.

The second section reviews organizational models for delivering guardianship services. The section begins with a chapter that describes many of the existing corporate guardianship programs in the United States. Subsequent chapters offer detailed descriptions of two public guardianship schemes and four private guardianship corporations.

TITLE: Intervention with at-risk and handicapped infants: From research to application

AUTHOR: D. D. Bricker (Ed.)

PUBLICATION INFORMATION: 1982

Pro ED
5341 Industrial Oak Boulevard
Austin, TX 78735

COST: $22.00

Leading infant researchers translate the latest data into practical systems, strategies, and procedures for intervention with "at-risk" and handicapped infants in this new volume. Experts in the field--scholars and field researchers--help translate their research findings into usable approaches in applied settings, eliminating the usual time lag so often found in the field of education...a lag sometimes lasting years; a lag that has historically separated research findings from practical application. These timely suggestions and procedures are appropriate for use by teachers, clinicians, program developers, and other professionals working with these infants and their families.

The presentation is broken down into 6 broad topic areas 1) theory to practice; 2) assessment issues; 3) assessment strategies, 4) environmental context, 5) social and developmental issues, and 6) intervention.

TITLE: Early childhood special education: Program development and administration

AUTHOR: Linden, T. W.

PUBLICATION INFORMATION: 1983

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $17.95

The text is intended to aid in planning, developing, implementing, and evaluating an early childhood special education program. It offers guidelines to assist in obtaining funding and also provides a foundation for developing quality-effective early intervention programs. There are detailed discussions of program conceptualization, resource coordination, student screening and assessment, curriculum design, administration and staff development, parent involvement, and program evaluation. An appendix provides a thorough outline of a sample program plan for early childhood special education. This is a valuable resource for the direct service provider, administrator, or planner who seeks a basic understanding of the current state of the art in this field.

ASSURING QUALITY SERVICES

The question of monitoring the quality of services is an ongoing concern, albeit for diverse reasons, for funders, public officials, administrators, advocates, and parents. These various interests are not mutually exclusive. In fact, a proper mix of different monitors can realize a balanced kind of oversight which is able to achieve far more then each of them operating in isolation. In this section we have attempted to offer a range of resources which explain the proper role of each of the elements in this closely allied system of quality assurance. A couple of guides which focus specifically on observing in residential settings are also included.

TITLE: Training exercises for human rights committee volunteers

AUTHOR: Laski, F., & Piccoli, M.

PUBLICATION INFORMATION: 1984

Community Human Rights Committee Project
Temple University
Ritter Hall Annex
9th Floor
Philadelphia, PA

These training exercises are practice sessions for people who participate on Human Rights Committees.

There are four major sections, including a section on individual rights issues, behavior modification issues, policy issues and human rights committee operational issues. Each section contains participatory exercises, including statements, letters and reports.

TITLE: Assessing and enhancing the quality of services: A guide for the human service field

AUTHOR: Bradley, V. J., et al.

PUBLICATION INFORMATION: 1984

Human Service Research Institute
120 Milk Street
8th Floor
Boston, MA 02109

COST: $15.00

This report should be must reading for anyone concerned with quality assurance. There are solid discussions of both the philosophical and practical issues in this area, as well as the description of numerous successful programs.

A primary focus of this report is the development of a cost effective system of quality assurance which goes beyond "paper" compliance and yet remains flexible enough to allow the growth of innovative services. A critique of the current system is offered. A theoretical framework which conceptualizes quality assurance as having five major components that have implications at both the policy and the operational level is outlined. The authors provide a good discussion of the complementary roles played by citizens, volunteers, professional peer monitors, private evaluators, consumers, families, advocates, and accreditation organizations in the assurance of quality services. The analysis of eight specific techniques of monitoring are organized according to the auspices under which they are best carried out.

The description of each technique includes an assessment of its uses, limitations, and applicability to specific situation. Chapter 4 is targeted on the regional official or private funder who is looking for a systematic procedure for analyzing and redesigning their quality assurance programs. The final section describes 22 quality assurance programs. It discusses each program's purpose, scope, implementation history, monitoring process, analytic process, control process, strengths, and limitations.

TITLE: A guide to monitoring residential settings

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1980

Human Policy Press
P.O. Box 127
University Station
Syracuse, NY 13210

COST: $4.00

Written for parents and advocates, this book is a guide to independent monitoring for institutions and community residential settings. The book describes different strategies for serving as an independent "watchdog." The chapters include: (1) introduction; (2) collecting public information (with a sample freedom of information request); (3) monitoring (with a sample observational checklist); (4) investigations; (5) understanding case records; (6) identifying gaps in community services; and (7) advocacy strategies. The appendix contains a descriptive report based on observations of two institutions.

TITLE: Observing community residences

AUTHOR: Taylor, S. J., & Bogdan, R.

PUBLICATION INFORMATION: 1980

Human Policy Press
P.O. Box 127
University Station
Syracuse, NY 13210

COST: $1.00

This brief, 13-page guide explains how and what to observe at community residential settings. It is not a checklist or evaluation instrument. Instead, this guideline lists an exhaustive set of questions to have in mind when visiting settings. Specific sections include: Location, building and yard, relations with the neighborhood, admission, operation, interior, habilitation and treatment, staff, residents, staff and resident communication, vocabulary, daily routines, clothing, personal appearance and hygiene, personal possessions, residents' rights, control, relations with family members, and records. This guide can be used to help parents, consumers, and citizens to monitor residential settings and to sensitize new staff members, parents, and others to features of a setting that enhance or detract from the quality of life.

TITLE: PASSING: Program Analysis of Service Systems' implementation of normalization goals

AUTHOR: Wolfensberger, W., & Thomas, S.

PUBLICATION INFORMATION: 1983

National Institute on Mental Retardation
Kinsmen NIMR Building
4700 Keele Street
Downsview, Ontario, Canada M3J 1P3

COST: $35.00

This book provides the guidelines for operationalizing the principle of normalization in an instrument for evaluating the quality of human services. In addition, the specific examples and discussion contained in this manual are intended to teach the principle of normalization to human service workers. The 42 PASSING ratings are broken down into two major categories: 1) Program elements related to client social image enhancement and 2) elements related to competency enhancement. Within both categories ratings are further subdivided as to whether they apply to a) the physical setting in which the service is located; b) the ways in which the service groups its clients and otherwise structures and supports relationships between them and other people; c) the activities, programs, and other ways in which the service structures the clients' time, and d) miscellaneous other factors including language, symbolism, and imagery which the service attaches to its clients. All in all, the in-depth analysis encouraged by this resource guides the reader through a rigorous examination of any service setting.

TITLE: Standards manual for facilities serving people with disabilities

AUTHOR: Commission on Accreditation of Rehabilitation Facilities (CARF)

PUBLICATION INFORMATION: 1985

Commission on Accreditation of Rehabilitation
Facilities
2500 North Pantano Road
Tucson, AZ 85715

COST: $25.00

This manual delineates the standards used by CARF when it reviews a rehabilitation facility for the purpose of professional accreditation. The format is to present a general principle of service followed by the specific standards which implement that principle. The standards are presented as they apply to organizations in general, programs in general, and finally to specific types of programs. The whole spectrum of rehabilitation programs, from inpatient services and residential services to jobs in industry and independent living, is discussed. Guidelines are provided concerning preparation for the survey teams visit and specifics of the accreditation process.

As in all such survey manuals the primary focus here is regulatory compliance, with its strong emphasis on issues of considerations in the management of a program or a facility, the reader should be reminded that the highest possible accreditation rating is meaningless unless it is informed by a commitment to the full social integration of the people whom the program serves.

TITLE: Program issues in developmental disabilities: A resource manual for surveyors and reviewers

AUTHOR: J. F. Gardner, L. Long, R. Nichols & D. M. Iagulli (Eds.)

PUBLICATION INFORMATION: 1980

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $18.95

Ostensibly written for certification reviewers and Title XIX (ICF/MR) surveyors, this book provides a good introduction to current trends and issues in the field of developmental disabilities. This edited book contains nine chapters: (1) Needs of Persons with Developmental Disabilities; (2) The Principle of Normalization: A Foundation for Effective Services; (3) Legal Rights of Developmentally Disabled Persons; (4) Implementing the Developmental Model; (5) A Behavioral Approach to Programming; (6) Interdisciplinary Team Process and Individualized Program Planning; and (7) Programming for the Severely/Profoundly Handicapped Person. The chapters contain marginal notes which cite ICF/MR standards relevant to the discussion. The book also contains a glossary of terms. People new to the field, or unfamiliar with current trends will find this book useful. Surveyors and reviewers will find that it provides a refreshing break from manuals which stress surveying procedures to the exclusion of philosophical and program issues.

TITLE: Monitoring the quality of life experienced in living arrangements: A guide to citizen participation

AUTHOR: Apolloni, T., Meucci, S., & Triest, G.

PUBLICATIONS INFORMATION: 1981

California State Council on Developmental Disabilities
1507 21st Street
Suite 320
Sacramento, CA 95816

This paper provides the rationale and a full range of concrete suggestions for establishing and maintaining a citizen monitoring system for community living arrangements. The point is made that citizen monitoring is not a replacement for professional oversight and review but acts as a supplement to these procedures. In particular a voluntary system is able to be sensitive and responsive to issues which professional reviews deal with in only a cursory fashion. Some of the topics covered in this paper are: A) organizing citizen monitoring, B) administration of a program, C) appropriate umbrella agencies, D) composition of a monitoring committee, E) recruiting members, F) training, G) guidelines for observers, H) follow-up, and I) sources of technical assistance. A model of a service review instrument (to help in structuring observations) is also provided.

TITLE: Monitoring community residences: Guidelines--Handbook

AUTHOR: Bersani, H. A.

PUBLICATION INFORMATION: 1984

A R C - Ohio
751 Northwest Boulevard
Columbus, OH 43212

These two resources are primarily intended to be used in conjunction with a day-long training session for voluntary service monitors. The Handbook is a resource for the monitors and the Guidelines is the actual monitoring instrument. The basis for this approach to monitoring is the sense that volunteer and parent monitors will view programs from a perspective which is very different from that of the professional auditor. The Handbook defines the role of the monitor and clarifies the meaning of normalization. The Guidelines provide a list of questions to be answered by the monitor as they relate to the following issues in residential settings: 1) rights; 2) the environment, physical and social; 3) use of community resources; 4) commitment to personal growth; and 5) staff. Both volumes contain useful bibliographies.

PROGRAMMING: INDIVIDUAL PLANNING

Individual planning, in any service setting, must be a sensitive, systematic process which seeks to address the gap between an individual's skills and the demands of his or her environment. It cannot be a merely mechanical process which is dependent on some pre-defined sequence of skill development, a cookbook of training programs, or the need to fill in the form because it is time for the "case" conference. In this section we offer: one resource which is intended as a consciousness raiser or sensitizer, one resource dealing with the mechanics of the team process and writing an individualized plan, and a number of resources, drawn from the educational literature, which outline an effective strategy for generating a functional, community-based picture of a person's programmatic needs.

ALSO SEE: the curriculum guides in the section on
Educational services.

TITLE: Getting to know you: One approach to service assessment and planning for individuals with disabilities.

AUTHOR: Brost, M. M. & Johnson, T. Z.

PUBLICATION INFORMATION: 1982

DHSS-DCS
P.O. Box 7851
Madison, WI 53707

This book describes one attempt to create an alternative approach to needs assessment and service planning for people with developmental disabilities. The authors don't believe that knowledge or understanding of a person's needs can be gained through administration of interview schedules, checklists or any other standardized procedures (most widely used in human services today). Instead they have developed an alternative and manageable way of gathering information that avoids treating people routinely or losing track of their uniqueness. This alternative approach to individual assessment and planning offers very helpful guidelines to insure that the services that are planned, purchased and delivered really respond to the individual's need.

The book is divided into two parts:

Part I contains a description of the approach to need assessment and planning that was developed and refined during 1979-1981 by staff of the Developing Individualized Service Option Project, Wisconsin.

Part II describes and critiques a training project carried out in LaCrosse, Wisconsin to teach people to use the need assessment and service planning process described in Part I.

The book is a very useful handbook for people whose jobs involve assessment/planning and for people involved in training others in assessment and planning. Much of the material is also a valuable resource for others, such as direct service providers, advocates, administrators, parents and consumers.

TITLE: A guide to personal futures planning.

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: (In press)

In G. T. Bellamy & B. Wilcox (Eds.) A comprehensive guide to the activities catalog: An alternative curriculum. Baltimore, MD: Paul H. Brookes Publishing Co.

A key element in an individualized service system is a planning process which brings together all of the people whose cooperation is essential for assuring the future quality of life of the individual of concern. O'Brien offers a forum for such an approach to planning which he calls "Personal Futures Planning." As O'Brien describes it the person's life is reviewed from the five perspectives of 1) community presence, 2) choice, 3) competence, 4) respect, and 5) community participation. It is his thesis that these five elements are the way most people define the quality of their lives. Within the framework of these themes the planning process then revolves around eight questions about the person's life:

1) What is the quality of the focal person's present life experience?

2) What is changing for the person or in the surrounding environment that is likely to influence the quality of the focal person's life?

3) What are the most important threats and opportunities to better life experience for the focal person?

4) What is the image of a desirable future for the focal person?

5) What are the most critical barriers to our moving toward the desirable future?

6) How will we most effectively manage these critical barriers and move toward the future we've defined?

7) What are the next steps?

8) Based on our discussions, do we want to make any statements about necessary changes in the capabilities of the service system?

The end result of this is a shared vision of the absolutely unique situation of a specific individual and a plan of action for moving toward that goal. The description of the meeting concludes with suggestions for assuring that the formulated plan is actually implemented.

TITLE: Individual program planning with developmentally disabled persons

AUTHOR: Parham, J. D., Rude, C., & Bernanke, P.

PUBLICATION INFORMATION: 1977

Research and Training Center in
Mental Retardation
Texas Tech University
Box 4510
Lubbock, TX 79409

This training package has three components:

1. Workbook: Individual Program Planning with Developmentally Disabled Persons.

COST: $10.00

2. Manual: How to Implement and Maintain an Individual Program Planning System.

COST: $4.00

3. Videotapes: Two 1 hour tapes available in various formats.

COST: Purchase/rental price varies with format.

This training package consists of workbooks for individual trainees, two videotapes to be used by the group in several training sessions, and a supervisor's manual. The videotapes present client behavior (used for practice and discussion) and informative lectures. The workbook contains most of the course content and the directions for proceeding through the sessions. The workbook also gives each participant a permanent record of his/her training experience and a reference source. The manual suggests ways of getting staff involved in training and of maintaining an IPP system once it is established.

The training package presents a single conceptual model of an individual program plan (IPP), which includes four basic parts: goals (to indicate the general aims of the program); objectives (to specify client behaviors and time limits for achieving them); strategies (to tell when and how the objectives will be achieved); and evaluation (to monitor both the process and outcome of the IPP). While examples refer to severely handicapped developmentally disabled persons, the concepts are broad enough to apply to all disability groups and are flexible enough to be adapted to specific agency needs.

The training requires six 2-hour training sessions. The course is instructor-free and is designed for use by a group of five to nine persons--preferably by an entire interdisciplinary team of persons working on a client's program. This group training experience is intended to facilitate a sharing of ideas, as well as a common understanding of what individual program planning is and how an interdisciplinary team can function.

As with most such packages which teach a process, the technical proficiency must be balanced by strong guiding principles. Also, it needs to be constantly restated that sensitivity to the input of the person who is being planned for is more crucial than all this emphasis on developing a smooth working "professional" team.

TITLE: Using the characteristics of current and subsequent least restrictive environments in the development of curricular content for severely handicapped students.

AUTHOR: Brown, L., Branston-McLean, M. B., Baumgart, D., Vincent, L., Flavey, M., & Schroeder, J.

PUBLICATION INFORMATION: 1979

Journal of The Association for the Severely Handicapped 4(4), 407-425.

The article presents an overview of integrated programming for the severely handicapped. The main pieces of the argument are: (1) severely handicapped people should not be compared with younger, non-handicapped people; (2) programs for the severely handicapped should use various adaptations to insure at least partial participation in chronologically age-appropriate, functional activities; (3) these programs should be future-oriented and affirmative (oriented to "current and subsequent environments"); (4) the article further argues that services for the severely handicapped should be varied, individualized, heterogeneous, flexible, evolving and able to change. In addition, it gives strategies and steps to achieve these objectives. The examples about the importance of integration with nonhandicapped people are particularly effective. Emphasis is upon personal dignity and self-esteem, along with the necessity to perform portions of skill sequences in functional ways.

TITLE: Mealtimes for Severely and Profoundly Handicapped Persons: New Concepts and Attitudes

AUTHOR: R. Perske, A. Clifton, B. M. McLean, & J. I. Stein (Eds.)

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $16.95

The term Mealtimes is an apt title for this marvelously written and useful book. This book does not simply describe proper "feeding" techniques for people with severe and multiple disabilities. It shows how mealtimes can be designed to be pleasant and enjoyable experiences.

Sensitively written and superbly edited, this book is a collection of articles by professionals, parents, people with disabilities, administrators, and others. The book starts out with an introduction written by Robert Perske entitled, "A Gentle Call to Revolution." Perske sets the tone for the book in this introductory chapter by stressing the need for "dignity, kindness, cooperation, and skill." The remainder of the book is divided into four sections: Value of Mealtimes, Creative Interactions, Creative Uses of People, and Helpful Settings.

This is not intended to be a how-to-do-it handbook. Instead, the purpose is "to allow a wide range of people to speak plainly about the fresh attitudes they have developed about mealtimes and the innovative things they are trying to do."

Anyone who works with people with severe and multiple disabilities should read this book. Parents, caregivers, and agency administrators will find it especially useful.

TITLE: Community instruction: A natural cues and correction decision model

AUTHOR: Ford, A., & Mirenda, P.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps
9(2), 79-88

In this article the authors provide the direct service worker in community-based educational, vocational, and residential programs with a clear concise outline of a skill development decision model. What is significant about this model is that it specifically focuses on the special problems which arise when instruction is undertaken in the non-laboratory conditions of real community environments. As opposed to much other work in special education literature the author's intent is to use naturally occurring cue and corrections and not artificially contrived behavioral interventions. This is a fine "how to" article which avoids the trap of merely telling the audience how one discrete intervention was carried out.

TITLE: Strategies of developing individualized recreational/leisure programs for severely handicapped students.

AUTHOR: Ford, A., Brown, L., Pumpian, I., Baumgart, D., Nisbet, J., Schroeder, J., & Loomis, R.

PUBLICATION INFORMATION: 1984

In N. Certo, N. Haring, & R. York (Eds.). Public school integration of the severely handicapped: Rational issues and progressive alternatives. Baltimore: Paul H. Brookes. (pp. 245-275)

COST: $19.45

The authors suggest that the recreational and leisure needs of severely handicapped persons is one crucial area in their lives which is often ignored in educational programming. The net result of this failure of the educational system is that the severely handicapped adult is left with a restricted repertoire of leisure skills and is often dependent on the limited number of organized, segregated, "special" leisure-time activities.

In outlining the strategies to be used to formulate an individualized recreation/leisure component for the school curriculum, the authors provide a very practical sketch of the ecological approach to community-based programming which should be usable in the full range of settings providing services to severely handicapped individuals. There are eight stages to the process: 1) conducting ecological inventories, 2) summarizing inventory information, 3) establishing priorities (this discussion is particularly thorough discussing 19 dimensions to be considered in establishing individual program priorities), 4) conducting a discrepancy analysis, 5) using partial participation and proposing individualized adaptations, 6) determining individualized objectives, and 7) designing the specifics of the individual's program.

TITLE: A strategy for developing chronological age appropriate and functional curricular content for severely handicapped adolescents and young adults.

AUTHOR: Brown, L., Branston, M. B., Hamre-Nietupski, S., Pumpian, I., Certo, N., & Gruenewald, L.

PUBLICATION INFORMATION: 1979

Journal of Special Education
13(1), pp. 81-90

The position of the authors of this article is that the learning characteristics of severely handicapped persons demand that the most efficient possible use be made of their limited tenure in the educational system. A model is provided for generating individualized educational programs for these persons which focuses on developing functional, age appropriate skills that can be utilized in the widest possible range of natural environments. Instead of viewing this curriculum as made up of discrete subject areas it is suggested that a "top-down" perspective be adopted. From this orientation curriculum is organized according to the four global environments or domains in which people are involved throughout their lives--Community, recreation/leisure, domestic, and vocational. While this article is specifically focused on the provision of educational services the ideas presented in it provide a useful framework for examining the issues in the life of a severely handicapped person at any age.

TITLE: Principle of partial participation and individualized adaptations in education programs for severely handicapped students.

AUTHOR: Baumgart, D., Brown, L., Pumpian, I., Nisbet, J., Ford, A., Sweet, M., Messina, R., & Schroeder, J.

PUBLICATION INFORMATION: 1982

Journal of the Association for Persons with Severe Handicaps
7(2), pp. 17-27.

In distinction from earlier models of instruction for severely handicapped individuals which generally seemed to regard the attainment of complete independence and total mastery of all aspects of a task as the only appropriate education goal, this article posits the value of partial participation and task adaptations. It affirms that all severely handicapped persons can acquire many skills that will allow them to function, at least in part, in a wide variety of non-segregated school and nonschool environments and activities. Six types of individualized adaptations are delineated. Clear guide lines for deciding when the use of partial participation and adaptations is appropriate are provided. And finally, an eight phase strategy for implementing this approach in any setting serving persons with severe disabilities is discussed.

TITLE: The importance of choice-making skills for students with severe disabilities

AUTHOR: Shevin, M., & Klein, N. K.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps
9(3), pp. 159-166.

This article raises the important issue of allowing persons with severe disabilities to have real opportunities to make choices. The authors contend that because of the degree of their disabilities and the nature of the environments within which they function it is necessary: 1) to specifically teach persons with severe disabilities culturally normative ways to express their choices and 2) to structure activities to enable them to exercise choice. Procedures are suggested for teaching choice-making skills, for integrating opportunities for exercising those skills throughout the day, and for fostering choice-making skills through the use of logical consequences. As with many JASH articles this article is written in terms of educational programming, but the points made here certainly have utility in any setting which provides services to severely disabled individuals.

PROGRAMMING: SERVING PERSONS WITH CHALLENGING BEHAVIORS

From the massive literature on behavioral programming we have selected a very small number of resources. Our criterion for selection was strict adherence to the guidelines of the Association for Persons with Severe Handicaps on intrusive interventions, which read as follows:

> Whereas, in order to realize the goals and objectives of The Association for Persons with Severe Handicaps, including the right of each severely handicapped person to grow, develop, and enjoy life in integrated and normalized community environments, the following resolution is adopted:
>
> Whereas, educational and other habilitative services must employ instructional and management strategies which are consistent with the right of each individual with severe handicaps to an effective treatment which does not compromise the equal important right to freedom from harm. This requires educational and habilitative procedures free from indiscriminate use of drugs, aversive stimuli, environmental deprivation, or exclusion from services; and
>
> Whereas, TASH supports a cessation of the use of any treatment option which exhibits some or all of the following characteristics: 1) obvious signs of physical pain experienced by the individual; 2) potential or actual physical side effects, including tissue damage, physical illness, severe stress, and/or death, that would properly require the involvement of medical personnel; 3) dehumanization of persons with severe handicaps because the procedures are normally unacceptable for nonhandicapped persons in community environments; 4) extreme ambivalence and discomfort by family, staff, and/or caregivers regarding the necessity of such extreme strategies or their own involvement in such interventions; and 5) obvious repulsion and/or stress felt by nonhandicapped peers and community members who cannot reconcile extreme procedures with acceptable standard practice;
>
> Resolved, that The Association for Persons with Severe Handicaps' resources and expertise be dedicated to the development, implementation, evaluation, dissemination, and advocacy of educational and management practices which are appropriate for use in integrated environments and which are consistent with the commitment to a high quality of life for individuals with severe handicaps.
>
> (Adopted October, 1981)

These guidelines mean that most of the standard materials on behavioral interventions were excluded from consideration. We feel that the highly vulnerable nature of the people who are the prime focus of this project justifies such rigid adherence to these guidelines.

SEE ALSO: curriculum guides, under Educational services, and Staff Training materials for for discussions of the basic principles and practices of Applied Behavior Analyses.

TITLE: A time-limited intensive intervention program model to support community placement for persons with severe behavior problems

AUTHOR: Donnellan, A. M., LaVigna, G. W., Zambito, J., & Thvedt, J.

PUBLICATION INFORMATION: 1985

Journal of The Association for Persons with Severe Handicaps
10, 123-131.

This article describes a program model for meeting the needs of a widely diverse range of people using nonaversive strategies to deal with their severe behavior problems in community environments. Follow-up data is presented which supports the effectiveness of the model. In addition, data from parents and an independent review committee provides support for the social validity of the programs goals and methods.

TITLE: The management of aggressive behavior

AUTHOR: Favell, J.

PUBLICATION INFORMATION: 1983

In E. Schopler, & G. Mesibov (Eds.), Autism in adolescents and adults (pp. 187-222). New York: Plenum Press.

This chapter focuses on the major issues related to aggression and its treatment. These issues include: factors maintaining aggression, treatment goals, an overall treatment strategy including methods of developing appropriate alternative behavior and methods of suppressing aggression, the use of psychotropic drugs, dealing with collateral changes in behavior, and methods of generalizing and maintaining durable improvement.

TITLE: Alternatives to punishment: Non-aversive strategies for solving behavior problems

AUTHOR: LaVigna, G. W., & Donnellan, A. M.

PUBLICATION INFORMATION: 1986

Irvington Press
740 Broadway
New York, NY 10003

This book provides a comprehensive overview of how to implement a positive approach to behavioral programming in the community. It reviews the standard behavioral practices and delineates how they can be implemented within this positive framework. This book will be particularly valuable to behavioral psychologists working with community programs.

TITLE: Modification of excess behavior: An adaptive and functional approach for educational and community contexts

AUTHOR: Meyer, L. H., & Evans, I. M.

PUBLICATION INFORMATION: 1986

In R. H. Horner, L. H. Meyer, & H. D. Fredericks (Eds.), Education of learners with severe handicaps: Exemplary service strategies (pp. 315-350). Baltimore: Paul H. Brookes Publishing.

The authors of this chapter give service providers an overview of the adaptive and function approaches which are available for addressing challenging behaviors in people with severe disabilities. They provide a summary review of the empirical evidence which supports the effectiveness of these approaches. This review demonstrates that the technological knowledge is adequate for dealing with behavior problems within the context of integrated community environments. What is demonstrated in this chapter is the ability to place this highly developed technology within a framework which sees it as a tool for improving the lives of individuals and not as an end in itself.

TITLE: Cognitive counseling & persons with special needs: Adaptive approaches to the social context.

AUTHOR: Lovett, H.

PUBLICATION INFORMATION: 1985

Praeger Publishers
521 Fifth Avenue
New York, NY 10175

COST: $16.95 (paperback).

This book is about seeing the unique value of every individual regardless of the labels society has pasted on them. Indeed, Lovett does write about the counseling--the true professional--relationship in the fullest sense: helping the individual have the greatest possible range of choices in his or her life. The forum for this discussion is provided as Lovett highlights the ways in which behaviorism, a powerful tool for aiding personal growth, has been transformed into a methodology for control. In particular, he shows how an emphasis on clinical research has led to the misuses of many interventions in the lives of people with severe disabilities. His central point is that by attempting to directly translate procedures used in highly controlled institutional setting into the real lives of people, service providers and their behavioral consultants have frequently lost sight of the individual they claim they are helping. Lovett sees the basic principle of behaviorism as remaining valuable, but points out how implementation is radically transformed when the social context of an intervention is taken into consideration.

Except for the title this book is written in a clear understandable style. Anyone with a minimal understanding of behaviorism should be able to learn from it. However, you will be disappointed if you pick this volume up looking for a how-to-do-it-manual of behavioral strategies. One of its central lessons is that all such "resources" will be most valuable when they find their way to the circular file.

Teachers, residential providers, and consultants will find Lovett rewarding reading. In addition this book may be particularly valuable as a tool for educating local "generic" mental health providers and beginning psychologists about people with severe and profound mental retardation. One of the most telling section contains the authors reflections on the inadequacy of his own professional preparation for working for people with severe disabilities.

And finally, make no mistake about it as Lovett speaks about the right to live in the community, freedom of choice, respect, and dignity he clearly means everyone. His numerous examples from his own experience make it clear that this man places no arbitrary limits on who is a member of the human community. His books should lead all of us who work for people with severe disabilities to seriously examine the attitudes we bring to our work.

TITLE: Gentle teaching: An alternative to punishment for people with challenging behaviors.

AUTHOR: McGee, J. J., Menousek, P. E., & Hobbs, D.

PUBLICATION INFORMATION: In press (To be published Spring 1987)

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities.
Teachers College Press, 1234 Amsterdam Ave., New York, NY, 10027.

This chapter is an excellent practical manual on approaches for working with people with challenging behaviors. The authors offer the "gentle teaching" approach as an alternative to punishment and aversive behavior management. "Gentle teaching" stresses the importance of integrating behaviorism with humanism. The manual provides a philosophical rationale for gentle teaching, a description of techniques, examples of gentle teaching, and an excellent section on "What you can try if. . ." This is one of the best resources available on how to deal with people with challenging behaviors in a humane and effective manner. The manual is directed toward caregivers and others who are directly involved in providing services.

TITLE: Analyzing the communicative functions of aberrant behavior

AUTHOR: Donnellan, A. M., Mirenda, P. L., Mesaros, R. A., & Fassbender, L. L.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps
9(3), pp. 201-212

The author suggest that when an individual lacks conventional modalities of communication they are likely to attempt to communicate using means which a service provider may perceive as problem behavior. Three types of interventions are offered to provide the severely handicapped persons with an alternative to this socially unacceptable type of communication. A strategy and an instrument for analyzing the communicative function of behavior (i.e., understanding the message the severely handicapped person is sending) is also provided. The perspective advocated in this article is significant because it reminds behavior modifiers that the person they are setting out to change has an individual point of view and may well be sending a message which is not being properly received.

TITLE: An educative approach to behavior problems: A practical decision model for interventions with severely handicapped learners.

AUTHOR: Evans, I. M., and Meyer, L. H.

PUBLICATION INFORMATION: 1985

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $19.95

This book presents a decision model, accompanied by detailed procedures for implementation, for dealing with the excess or problem behavior of persons with severe disabilities in a functional and adaptive way. Practitioners are provided with a practical, step-by-step model for planning interventions with people with severe problem behaviors in the context of habilitative, community-based programs across the school years and beyond. Separate chapters describe current "most promising practices" in educational curricula for learners with severe handicaps into which this approach should be integrated; the empirical research base on causes of and interventions with severe behavior problems; a field-tested decision model to select priority intervention goals within the context of the IEP; strategies to intervene with excess behavior in normalized, community environments; and evaluation principles and procedures to judge the significance of interventions. Each of the procedures and strategies described in the book have been demonstrated to be effective in integrated, community settings, and all are consistent with the TASH resolution on intrusive interventions.

The following articles describe particular non-intrusive interventions which have been effectively used in community settings.

Barton, L. E., & Barton, C. L. (1985). An effective and benign treatment of rumination. Journal of the Association for Persons with Severe Handicaps, 10, 168-171.

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. Journal of Applied Behavior Analysis, 18, 111-126.

Donnellan, A. M. (1984). The criterion of the least dangerous assumption. *Behavioral Disorders*, *9*, 141-150.

Evans, I. M., & Voeltz, L. M. (1982). *The selection of intervention priorities in educational programming of severely handicapped preschool children with multiple behavior problems* (ERIC report # ED 240 765). Honolulu: University of Hawaii Departments of Psychology and Special Education.

Favell, J. E. (1973). Reduction of stereotypes by reinforcement of toy play. *Mental Retardation*, *11*, 21-23.

Favell, J. E., McGimsey, J. F., & Schell, R. M. (1982). Treatment of self-injury by providing alternate sensory activities. *Analysis and Intervention in Developmental Disabilities*, *2*, 83-104.

Gaylord-Ross, R. (1980). A decision model for the treatment of aberrant behavior in applied settings. In W. Sailor, B. Wilcox, & L. Brown (Eds.). *Methods of instruction for severely handicapped students* (pp. 135-158). Baltimore: Paul Brookes Publishing.

Konczak, L. J., & Johnson, C. N. (1983). Reducing inappropriate verbalization in a sheltered workshop through differential reinforcement of other behavior. *Education and Training of the Mentally Retarded*. *18*, 120-124.

O'Neil, P. M., White, J. L., King, C., & Carek, D. (1979). Controlling childhood rumination through differential reinforcement of other behavior. *Behavior Modification*, *3*, 355-372.

Peterson, R., & Peterson, L. (1968). The use of positive reinforcement in the control of self-destructive behavior in a retarded boy. *Journal of Experimental Child Psychology*, *6*, 351-360.

Rose, T. L. (1979). Reducing self-injurious behavior by differentially reinforcing other behavior. *AAESPH Review*, *4*, 179-186.

Smith, M. D. (1985). Managing the aggressive and self-injurious behavior of adults disabled by autism. *Journal of the Association for Persons with Severe Handicaps*, *10*, 228-232.

Woods, T. (1982). Reducing severe aggressive and self-injurious behavior: A nonintrusive, home-based approach. *Behavioral Disorders*, *7* (3), 180-188.

PROGRAMMING: SERVING PEOPLE WITH PHYSICAL DISABILITIES

SEE ALSO: Mealtimes for Severely and Profoundly Handicapped Persons

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TITLE: Low cost approaches to technology and disability

AUTHOR: Dixon, G. L., & Enders, A.

PUBLICATION INFORMATION: 1984

National Rehabilitation Information Center
D:ATA Institute
Catholic University of America
4407 8th Street, N. E.
Washington, DC 20017

COST: $7.50

Disguised as an annotated bibliography, this report is a gold mine for disabled persons, their families, and many direct service providers. It makes accessible for the first time, in one place, the disparate and often hidden literature on low cost technical aids for disabled persons.

This is not another book recounting the wonders of the latest high-tech innovations. Rather, this resource provides ready access to the many simple devices and adaptations which meet the needs of so many disabled persons. In the past the unavail-ability of a central source for this information has meant that people who see these relatively simple needs have had to constantly reinvent the wheel. This resource fills that void. The text reviews the authors' perspective on this material, highlights some as yet unfilled needs in this area, provides the two authors lists of what they see as the best resources, and ends with 37 pages of annotated resources.

TITLE: Deinstitutionalization and normalization of persons with mental retardation: The role of a physical therapist in community placement

AUTHOR: Schleichkorn, J.

PUBLICATION INFORMATION: 1981

Physical Therapy
61(10), 1438-1441

An historical review of institutionalization of the retarded is presented together with a description of the role that the physical therapist can play in developing programs for home care providers. A program involving 48 individuals with mental retardation in 12 homes is described together with the training program established by a physical therapist.

TITLE: Handling, positioning, and feeding the physically handicapped

AUTHOR: Utley, B. L., Holvoet, J. F., & Barnes, K.

PUBLICATION INFORMATION: 1977

In E. Sontag, J. Smith, & N. Certo (Eds.) Educational programming for the severely and profoundly handicapped. Reston, VA: Council for Exceptional Children

This is a technical, but clearly written article that describes handling, positioning, and feeding techniques for people with severe physical and multiple disabilities. The authors address assessment and measurement, proper positioning, task analysis, feeding techniques, precautions, and sources of additional information. They provide a step-by-step approach and offer numerous examples. The article is directed toward people who work directly with people with severe disabilities.

TITLE: Approximating the norm through environmental and child-centered prosthetics and adaptive equipment

AUTHOR: Campbell, P. H., Green, K. M. & Carlson, L. M.

PUBLICATION INFORMATION: 1977

In E. Sontag, J. Smith, & N. Certo (Eds.) Educational programming for the severely and profoundly handicapped. Reston, VA: Council for Exceptional Children

This article, which is technical, but clearly written provides practical information on selecting equipment, designing prosthetics, and developing programs for people with severe physical and orthopedic impairments. The article contains numerous illustrations and case examples. The conclusion lists sources of additional information. The article is written for people involved directly in services for people with severe disabilities.

TITLE: Handling the young cerebral palsied child at home (Second Edition)

AUTHOR: Finnie, N. R., Bavin, J., Muellere, H., Gardner, M., & Haynes, U.

PUBLICATION INFORMATION: 1975

New York: Dutton-Sunrise

This is a clearly written and practical guidebook on handling children with cerebral palsy and other orthopedic disabilities. written by medical and other health-related professionals, the book discusses movement, basic principles of handling, toilet training, dressing, feeding, speech, carrying, adaptive equipment and aids, grasp and manipulation, play and other aspects of caring for children with severe physical impairments. The book is filled with clear illustrating that demonstrate the points described in the text. The back of the book contains several useful appendices on the early stages of normal development, a questionnaire for parents and resources in the United States (the authors of the book are from England), a glossary of medical terms, a reading list, and a list of resources for equipment and accessories. This is an excellent book for parents, foster families and direct care staff who deal with children with severe physical disabilities.

TITLE: Managing physical handicaps: A practical guide for parents, care providers, and educators

AUTHOR: Fraser, B. A., & Hensinger, R. N.

PUBLICATION INFORMATION: 1983

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $19.95

This book is intended to serve two purposes a) to introduce physical therapists to the problems of severely handicapped individuals, and b) to familiarize others with the fields of PT and orthopedics. It was written based on the experience of providing services to severely handicapped students in the Wayne County (Michigan) public schools. Although it was written from the perspective of in-school services, this book is a valuable resource for any setting where there are severely physically handicapped persons.

The presentation falls into three major sections: The first emphasizes the need to look beyond the disability and see the person in need of services. It also describes the nature of various handicapping conditions and offers a model for the delivery of PT/orthopedic services. The second section describes and explains a wide range of physical handicaps. The final section discusses techniques for communication with, handling, and transporting severely impaired persons.

MEETING PEOPLE'S MEDICAL NEEDS IN THE COMMUNITY

People with extensive medical needs are being supported in homes throughout of the country. As with other people, children and adults with extensive medical needs also have the same basic needs as all of us (e.g., the need to be loved, and the need for a home). The types of additional supports that will be needed for a person with extensive medical needs to live in the community will vary from person to person. The additional supports needed are usually not complex, but may involve consultation by medical personnel, the availability of specialized equipment, and the availability of accessible support services.

TITLE: Home care for the chronically ill or disabled child: A manual and sourcebook for parents and professionals.

AUTHOR: Jones, M. L.

PUBLICATION INFORMATION: 1985

New York: Harper & Row

COST: $12.95

This book, written by the mother of a severely multiple handicapped child, is a marvelous compendium of information on home care for people with multiple disabilities and/or serious medical problems. It is a must for anyone who is involved in maintaining an individual with multiple disabilities in a family home. It provides good basic how-to information which effectively demystifies home nursing procedures. Topics range from attitudes and parental feelings to techniques for tube-feeding and administering oxygen. Many useful illustrations and charts are also provided.

TITLE: Home care: A challenging opportunity

AUTHOR: Stein, R. E. K.

PUBLICATION INFORMATION: 1985

Children's Health Care,
14(2), 90-95.

This six-page article addresses a number of issues regarding home care for the chronically ill child as an alternative to in-patient hospital care. Within the context of the article, the author raises six questions regarding home care, and proceeds to answer them with progressive, current and well thought-out discussion. Specifically the questions asked are: What is home care? Why is home care an issue now? Who can benefit from home care? What are the ingredients for a successful home care program? How should we evaluate the outcomes, and what do we currently know about these outcomes? What are some of the pitfalls of home care? Clearly written, this article appears appropriate for a wide range of readers interested in this topic.

TITLE: The family as care manager: Home care coordination for medically fragile children

AUTHOR: Kaufman, J., & Lichtenstein, K. A.

PUBLICATION INFORMATION: 1986

Coordinating Center for Home and Community Care, Inc.
P.O. Box 613
Severn Professional Building
Millersville, MD 21108

COST: $4.95

This workbook is an extremely valuable tool for parents and families who choose to care for their "medically fragile" child at home. Written clearly and concisely, it provides necessary and practical organizational information, as well as being an educational and informational resource tool.

Divided into four sections, Section I, the "Introduction," gives a brief review of what is entailed in a discharge plan, a very thorough needs assessment to be completed by the family, and a redefinition of "care manager." Section II, "Families as Care Managers," describes the five roles which families must assume as care managers: the role of medical manager, financial planner, educational advocate, resource specialist, and employer. Included within each topic are practical checklists and worksheets. Section III, "Maintenance of Records," explains the need for families to maintain an organized system of record keeping and delineates which information to include in an open file. Section IV, "Conversation with Families: Recurring Themes," lists those themes and concepts that the authors found to be common to families exploring the "home care frontier."

TITLE: Meeting the challenge of disability or chronic illness - A family guide

AUTHOR: Goldfarb, L. A., Brotherson, M. J., Summers, J. A., & Turnbull A. P.

PUBLICATION INFORMATION: 1986

Paul H. Brookes Publishing Co., Inc.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $14.95

This book is an extremely unique and valuable tool, written for all families experiencing any type of situation involving care of an ill or disabled family member. It is also an important resource for professionals working with families.

Filled with practical worksheets, activities and exercises, it provides information and techniques for family members to utilize in coping with their particular situation.

Part I, "Taking Stock," discusses methods of coping, relying upon one's value system, and various types of social and professional support. Part II, "Problem Solving," deals with family communication, problem definition, brainstorming for solutions, evaluation of alternatives, and action toward solving problems. The authors also include an Appendix of Resources, which contains a number of bibliographies on various subjects and a list of support organizations.

TITLE: Handbook for parents

AUTHOR: Mikol, M., Shannon, K., & Schuberth, K.

PUBLICATION INFORMATION: 1984

SKIP (SICK KIDS need INVOLVED PEOPLE), Inc.
National Headquarters
216 Newport Drive
Severna Park, MD 21146

This handbook was prepared as a resource to families who choose to care for their technology dependent children at home. The handbook includes a plethora of practical information such as emergency and back up checklists, equipment worksheets, selected references, information on home care, documentation hints and information on SKIP. It is clearly written and would probably be a useful resource to service providers as well as to families.

TITLE: Chronically ill children in America

AUTHOR: Hobbs, N., Perrin, J., Ireys, H., Moynihan, L., & Shayne, M.

PUBLICATION INFORMATION: 1984

Rehabilitation Literature, (1984, July/August). 45(7-8), 206-213.

This article discusses the commonalities among severe chronic illnesses of childhood, reviews the definition of chronicity and severity, describes the current organization of care, costs of care and financing of care, identifies basic principles that should underlie public policy formation, and delineates the issues involved in systems change. A good resource for professionals, policy analysts, planners, and others involved in long-term policy formation.

TITLE: Assessment and planning for health professionals

AUTHOR: Green-McGowan, K. & Barks, L. S.

PUBLICATION INFORMATION: 1985

KMG Corporation
P.O. Box 2534
Peachtree City, GA 30269

The manual is an excellent resource covering such issues as the causes of health risk for people labelled as "medically fragile", methods of collecting information including interviewing techniques and observation of the person, an evaluation schema for the neurological, musculoskeletal, respiratory, gastrointestinal/urinary, endocrine, behavioral and nutrition/eating systems, and information on the development of health improvement goals.

The assessment methodology was developed by KMG Corporation specifically for use with people labelled as "medically fragile" in order to identify and categorize their genuine level of health risk and to focus on the management methodology of improving those risks. The manual is written specifically for health professionals and has limited applicability for non-health professionals.

TITLE: Medical care of the deinstitutionalized mentally retarded

AUTHOR: Merker, E. L., & Wernsing, D. H.

PUBLICATION INFORMATION: 1984

American Family Physician,
29(2), 228-233.

It is sometimes asserted that community doctors are not familiar with some of the concerns surrounding the medical care of people who have a history of life in an institution where they may have been exposed to Hepatitis B or been administered massive doses of unneeded drugs. Merker and Wernsing provide an overview of the role of the community physician and special concerns as they relate to patients with developmental disabilities. They highlight the significant contribution a community physician can make in the meeting the needs of these people. They outline the major "specialized" medical issue which may arise. They indicate that the family practice with which they are associated has been able to meet these needs including management and reduction or elimination of psychotropic medications.

Some other useful resources for community physicians include:

A Bibliography:

Reutig, N. (1985). Pharmacotherapy and mental retardation/developmental disabilities: A bibliography (Special emphasis on non-institutionalized populations). Psychopharmacology Bulletin, 21(2), 329-333.

A Physician Medication Monitoring Form:

Kalachnik, J. E., Miller, R. F., Jamison, A. G., & Harder, S. R. (1983). Results of a system to monitor effects of psychotropic medication in a applied setting. Psychopharmacology Bulletin, 19(1), 12-15.

A Tardive Dyskinesia Rating Scale for People with Developmental Disabilities:

Sprague, R. L., Kalachnik, J. E., Breuning, S. E., Davis, V. J., Ullman, R. K., Ciliary, S., Davidson, N. A., Ferguson, D. G., & Hoffner, B. A. (1984). The dyskinesia identification system--Coldwater (DIS-Co): a tardive dyskinesia rating scale for the developmentally disabled. Psychopharmacology Bulletin, 20(2) 328-338.

PROGRAMMING: DEVELOPING FUNCTIONAL SKILLS

TITLE: Learning steps: A handbook for persons working with deaf-blind children in residential settings

AUTHOR: Rowin, C.

PUBLICATION INFORMATION: 1976

California State Dept. of Education
Southwestern Region Deaf-Blind Center
Sacramento, CA

This helpful handbook was originally developed by the Southwestern Region Deaf-Blind Center, one of ten such centers established by the federal government in response to the needs of children who were born with combined auditory and visual impairments as a result of the 1963-64 rubella epidemic. The handbook is written in a relaxed and logical manner, presenting information on sensory disabilities, health, discipline, language, and play as well as specific instructions on activities which will foster growth in skill areas such a body movement, eating, dressing, toilet training, personal hygiene, and play. The handbook also contains an introductory section on the manual alphabet and basic sign language. The handbook is liberally illustrated throughout and could be used to help parents, siblings, babysitters, community residence staff, teachers, teacher aides, and other "direct service" audiences in gaining an understanding of the characteristics and learning needs of children with auditory/visual impairments. Much of the material would also be quite relevant to persons involved with any type of child with multiple disabilities. The language is clear, the suggested activities are meaningful, and the expectations are positive. An excellent resource.

TITLE: Teaching self care to severely handicapped students

AUTHOR: Campbell, P.

PUBLICATION INFORMATION: 1982

ERIC Document 231 126

Children's Hospital Medical Center
281 Locust Street
Akron, OH 44308

COST: $9.50

The manual provides guidelines for using the problem-oriented approach to teach the self-care skills of self-feeding, dressing, and toileting to severely handicapped students. The approach consists of identifying the problem that is an obstacle to acquisition of a particular skill, selecting and evaluating intervention techniques, and establishing written objectives. General guidelines include explanations of alternative intervention (e.g., positioning equipment) and instructional strategies; ways to use instructional strategies (such as what and how to teach, and how to determine antecedent conditions and consequent events); and instruction for use of the manual. Guidelines are provided for five self-feeding skills (e.g., finger feeding, spoon feeding, cup drinking); four dressing skills (e.g., undressing, shoe tying); and six toileting skills (e.g., bladder training, transfer on/off toilet). The following components usually are included for each of the self-care skills: general discussion; diagrammed training sequences showing component areas (matched with normal developmental milestones); expected outcomes; task sequences; essential prerequisite skills; training objectives; diagrammed training chart (to determine where to begin training); diagrammed assessment strategy chart (to identify problem, select strategy, observe child, and interpret results); instructional strategies; instructional flow chart; recording form; behavior graph; descriptions of adaptive devices; and a reference section. Sources of adaptive equipment are listed with addresses and such categories as "transportation" and "adaptive chairs."

TITLE: Functional living skills for moderately and severely handicapped persons

AUTHOR: Wehman, P., Renzaglia, A., & Bates, P.

PUBLICATION INFORMATION: 1984

Pro Ed
5341 Industrial Oak Boulevard
Austin, TX 78735

COST: $18.00

This text describes how functional and age-appropriate programs can be implemented for moderately and severely handicapped adolescents and adults. Major areas of focus include domestic living, community mobility and social interaction training, leisure skill instruction, vocational training, and advocacy. Each chapter provides instructional guidelines for the practitioner as well as references to the current literature. This is the first book to integrate the literature in this important area.

The contents of this book are: 1)introduction; 2) community based living facilities; 3) domestic/home living skills; 4) community mobility; 5) social interpersonal skills development; 6) leisure skill instruction; 7) sheltered employment; 8) competitive employment; 9) functional academics; 10) advocacy and community skill integration.

TITLE: Unobtrusive training: A home-centered model for communication training

AUTHOR: Wulz, S. U., Myers, S. P., Klein, M. U., Hall, M. K., & Waldo, L. J.

PUBLICATION INFORMATION: 1982

Journal of The Association for the Severely Handicapped 7(2), 36-47

Language training for severely developmentally delayed children in the home should be as undisruptive as possible and should use natural training contexts, emphasize functional responses, and provide natural reinforcers or consequences. After identifying the communicative contexts teaching the response is accomplished through reinforcement, modeling, and incidental teaching. This article should be a valuable resource for parents and professionals who are working with them.

TITLE: Functional signs: A new approach from simple to complex

AUTHOR: Bornstein, H., & Jordan, I. K.

PUBLICATION INFORMATION: 1984

Pro ED
5341 Industrial Boulevard
Austin, TX 78735

COST: $22.00

This is a dictionary of 330 American Sign Language signs for the handicapped. Helpful to teachers, speech-language pathologists and parents teaching the handicapped to sign, it shows where and how to begin teaching the sign if the whole sign cannot be produced. It provides a basic, functional vocabulary for the handicapped. The dictionary analyzes each sign's function and usefulness to the learner, as well as its representational value and physical and motoric characteristics. Each sign has been analyzed for a percentage of comprehensibility.

TITLE: Age-appropriate recreation programs for severely handicapped youth and adults

AUTHOR: Wehman, P., Schleien, S., & Kiernan, J.

PUBLICATION INFORMATION: 1980

Journal of The Association for the Severely Handicapped
5(4), 395-407

This article identifies the problem of acquiring and generalizing age appropriate recreational skills as one of the most significant obstacles to full integration of persons with severe handicaps. Two types of intervention are discussed: 1) Programmatic adaptations which include material, procedure/rule, skill sequence, and facility modifications; and 2) Instructional techniques. A case study of teaching a multiply handicapped woman to use a camera is presented as an example.

This paper gives educators and residential providers a number of valuable suggestions for addressing the need of severely handicapped persons to develop a range of recreational skills.

TITLE: Review of task analytic leisure skill training efforts: Practitioner implications and future research needs

AUTHOR: Nietupski, J., Hamre-Nietupski, S., & Ayres, B.

PUBLICATION INFORMATION: 1984

Journal of The Association for Persons with Severe Handicaps
9(2), 88-97

While this article is primarily a literature review of research on the development of leisure skills with severely handicapped individuals, two facets of it are of value to direct service providers: 1) the summary of the research provides a quick overview of the many diverse recreational activities which have been taught to severely handicapped persons; 2) the section headed "Implications for practitioners" in nine point synthesizes the key factors to be considered in implementing a program of leisure skill development.

TITLE: Longitudinal leisure skills for severely handicapped learners: The Ho'onanea curriculum component

AUTHOR: Wuerch, B. B., & Voeltz, L. M.

PUBLICATION INFORMATION: 1982

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $17.95

This book presents in detail all the components needed to implement a curriculum component to develop independent leisure activity skills in learners with severe disabilities in home, school and community environments. Procedures for assessing learner interests and skills, selecting appropriate leisure activity goals and interventions, implementing data-based instructional programs, home-school program coordination and collaboration, and evaluation of all aspects are included. Ten leisure activities which were judged to meet normalization, individualization and environmental needs of learners with severe disabilities were identified for the core curriculum, and field-tested, validated instructional sequences and strategies are presented for each of these. All project components are tested over a three year period of time with more than 50 severely to profoundly handicapped (including autistic and severe multi-handicapped learners) students, primarily teenagers, in public and private school settings in the state of Hawaii.

TITLE: Leisure programs for handicapped persons: Adaptations, techniques, and curriculum

AUTHOR: Wehman, P., & Schleien, S.

PUBLICATION INFORMATION: 1981

Pro-Ed
Austin, TX

COST: $15.00

This manual provides the information necessary to develop individualized instructional programs or leisure-time activities for handicapped adults or children. It includes data-based case studies which demonstrate the validity of the selected skills proposed in the curriculum chapters. The ten chapters discuss: normalization, leisure skills assessment, leisure instruction, adapting leisure skills, curriculum design and format, hobbies, sports, games, object manipulation, and program implementation.

TITLE: Participation: Expanding community and leisure experiences for people with severe handicaps

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1981

G. Allan Roeher Institute
Kinsmen Building
York University
4700 Keele Street
Downsview, Ontario, Canada M3J 1P3

COST: $12.50

This book grew out of a collective effort of a group of people in Canada known as the Recreation Council of the National Institute on Mental Retardation. The book is designed to assist communities in the initiation, planning and implementation of a process for expanding community and leisure experiences to include people with severe handicaps. The author sees community integration as a process and each chapter in the book represents one step in this process:

Step One: Generating interest in the participation of individuals with severe handicaps.

Step Two: Identifying and developing community support.

Step Three: Implementing plans.

Step Four: Preparing support persons.

Step Five: Expanding community and leisure experiences.

The book provides good and practical guidelines through each of the five steps. The process described in their book will be very helpful for those who want to enable people with severe handicaps to participate in a wide range of community and leisure experiences. The author also gives advice on how to overcome the barriers that may be involved.

TITLE: Recreation integration: Issues and alternatives in leisure services and community involvement

AUTHOR: Hutchison, P., & Lord, J.

PUBLICATION INFORMATION: 1979

G. Allan Roeher Institute
Kinsmen Building
York University
4700 Keele Street
Downsview, Ontario, Canada M3J 1P3

COST: $15.00

The focus of this book is leisure and community involvement for individuals who have disabilities. The authors emphasize the potential of recreation and leisure activities to personal-social fulfillment and meaningful ways of participating and contributing to the community, and developing close relationships with non-disabled persons.

The book is divided into seven chapters. This first chapter discusses the importance of play, recreation, and leisure in peoples lives. In chapters two and three the authors identify and analyze some of the problems within society and human services (both in general and in relation to recreation) which affect individuals with disabilities and prevent their involvement in the community. The authors also suggest what changes are needed to enhance community participation of people with disabilities and discuss the ideology upon which these changes are based. Chapters four, five and six deal with principles to enhance personal-social skills and confidence and principles to improve community settings for integration of recreation and leisure activities. The authors also discuss the importance of educating consumers, parents, advocates and the general public about leisure and integration and emphasize the importance of providing people with the support they need to reach the goal of community integration. The last chapter deals with how to develop, implement and evaluate a comprehensive recreation integration plan.

This book deals largely with the principles underlying successful community participation of people with disabilities through recreation and leisure activities. It does not give detailed guidelines for everyday practice. This book may therefore be of interest to those who are interested in the principles of normalization and their implementation in human services. The book should also be helpful for those who are interested in using recreation and leisure activities to enhance community participation of people with disabilities.

PROGRAMMING: STAFF TRAINING

Most of the material on staff training provides information in the following areas: health and safety, behavior management, understanding mental retardation, managing a household, writing program plans, leisure activities, and a short discussion of normalization. In general these resources seem geared to situations which serve mildly and moderately disabled people, since many of them fail to address the special problems of people with a more severe level of intellectual impairment and/or multiple disabilities. Also, they fail to inculcate in the staff person a sense of him or herself as the primary vehicle for facilitating the handicapped person's integration into the community. Indeed, in most cases this crucial issue and its subtle implications are often completely lost in the midst of procedures for managing a "residential facility."

To reiterate, these materials are "all right" as far as they go, but a discussion of the factors which distinguish the skills needed by a staff person working in a community service system from the skills of an institutional employee is often lacking.

TITLE: A reconceptualization of the role of the residential services provider.

AUTHOR: Knoll, J. & Ford, A.

PUBLICATION INFORMATION: In Press (To be published Spring 1987)

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.) Community integration for people with severe disabilities.
Teachers College Press, 1234 Amsterdam Ave., New York, NY, 10027.

This article presents an alternative conceptualization of the role of staff members who work directly with people with severe disabilities. The authors contend that most residential staff people are currently trained for managing a facility rather than supporting individuals in the community. As an aid in moving away from this system, they outline some of the major tensions which arise as staff people begin to see their role in a new way, a number of principles to help guide this refocusing of responsibility, and a series of strategies to help staff people plan for an individual.

TITLE: Managing group homes: A training manual

AUTHOR: T. McCarthy (Ed.)

PUBLICATION INFORMATION: 1980

TMAC Behavior Development
P.O. Box 140496
Nashville, TN 37214

COST: $14.95

Intended for group home managers, the book tells what the regulations are regarding the mentally retarded and provides information on compliance. Following an introductory chapter on mental retardation are eight self study units on the following topics (sample subtopics are in parentheses): normalization (assuring respect for residents' dignity, assuring residents' rights to personal possessions), human rights (implementing habilitation goal training, preparing for a monthly progress review, preparing for an annual progress review), resident records (organizing a resident record, writing progress notes, reporting incidents and injuries), behavior technology (reinforcing resident behaviors, utilizing graduated guidance, measuring progress with graduated guidance), home management (assuring home cleanliness, assisting with resident finances, organizing resident activity schedules, managing fire safety, taking severe weather precautions, managing staff changeover), food services (planning menus, preparing and serving a meal, cleaning the kitchen and eating area), leisure activities (organizing a recreation program), and home nursing (administering oral medication, measuring oral and auxiliary body temperature, assisting with oral hygiene, dealing with a grand mal seizure). Each study unit includes a text and a list of study question, as well as one or more on the job guides to performing the skills covered in the unit. OJT projects usually contain a list of directions and work sheets. Appended are the 1968 Declaration of General and Special Rights of the Retarded from the International League of Societies for the Mentally Retarded and the United Nations Declaration on the Rights of Mentally Retarded Persons.

TITLE: Resident manager education: A curriculum model for educating foster parents and group home personnel

AUTHOR: Provencal, G., & Evans, D.

PUBLICATION INFORMATION: 1977

Macomb-Oakland Regional Center
16200 Nineteen Mile Road
Mt. Clemens, MI

This training manual present a curriculum model which specifies for each content area: 1) the learning objectives, 2) stimulants for discussion, 3) a list of resources including possible sources for expert presenters, and 4) a reading list. The specific content is left to the individual user to develop. The material is divided into preservice and inservice modules. The preservice topics include: 1) orientation to mental retardation, 2) maintaining healthy environments and providing emergency care, 3) fire and safety issues, 4) administrative responsibilities, 5) elements of programming and 6) normalization. The inservice topics are 1) managing behavior, 2) recreation and leisure, 3) educational considerations, 4) community placement, 5) relations with natural families, and 6) thoughts on sexuality. This training program has high potential in the hands of a skilled instructor who will use it for all it is worth. However, as in most staff training material the need for residential staff to constantly focus on facilitating integration, especially for individuals with severe disabilities, is not adequately addressed.

TITLE: Training supervisor's handbook for managing group homes: A training manual

AUTHOR: T. McCarthy (Ed.)

PUBLICATION INFORMATION: 1980

TMAC Behavior Development
P.O. Box 140496
Nashville, TN 37214

COST: $34.95

The training supervisor handbook is designed for evaluating the self study and on the job training (OJT) performance of home manager candidates in community agencies providing residential services for mentally retarded persons. Answer keys for study questions and unit quizzes, and OJT project evaluation checklists correspond to units in the training manual which cover the following areas: introduction to mental retardation, normalization, human rights, resident records, behavior technology, home management, food service, leisure activities, and home nursing. Also provides a sample group home manager individual training record form.

TITLE: Behavioral habilitation through proactive programming

AUTHOR: Bernstein, G. S., Ziarnik, J. P., Rudrud, E. H., & Czajkowski, L. A.

PUBLICATION INFORMATION: 1981

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624

COST: $18.95

This book is intended as a basic training program for direct service providers. It is particularly targeted on developing a behavioral approach in paraprofessionals (in residential, educational, or vocational programs) who lack a previous background in working with persons with developmental disabilities.

The authors stated intent is to foster the development of a proactive perspective in direct service workers. They feel that if workers are trained from this perspective they will not find themselves in a situation where their job is seen only as the constant reacting to a new unforeseen crisis. There are brief overviews of developmental disabilities, the rationale behind community based programming and normalization. The bulk of the book is a course in behavioral programming which includes:

1) the planning process; 2) writing plans and objectives; 3) measuring, recording, and reporting behavior; 4) principles of behavior management; 5) strategies for increasing, decreasing, and teaching behavior; 6) maintenance and generalization of behavior; and 7) a systematic approach to programming. The final five chapters briefly deal with 1) instructional materials, 2) administrative skills, 3) organizational development and personnel management, 4) effective management, and 5) accessing community and professional resources.

As far as this book goes it is a good resource. However, with the sole exception of the brief discussion of normalization, it fails to give the reader a clear orientation towards community integration. Hence, if this is the only resource used in staff development, it has the potential for training competent technicians who can change behavior but lack principles to guide them in the use of this powerful technology.

ACHIEVING COMMUNITY ACCEPTANCE

The problem of communities' unwillingness to accept disabled people into their neighborhoods remains one of the major difficulties confronting the establishment of a community-based service system. While some of the problems may be rooted in the kind of services which providers seek to setup (i.e., too big, too institution-like, out of synch with the character of the neighborhood, etc.), others reflect deep-seated social prejudices. These later difficulties will be dispelled only by experience and a long-term educational effort. The resources included in this section attempt to address both long-term (attitude change) and short-term (e.g., getting through the site selection process) solutions to the problems of community acceptance.

TITLE: The effects of group homes on neighboring property: An annotated bibliography

AUTHOR: Mental Health Law Project

PUBLICATION INFORMATION: 1986

Mental Health Law Project
2012 L Street, N. W.
Suite 800
Washington, DC 20036-4909

This paper provides a brief synopsis of each of 40 studies that have examined the effects of group residential settings on the neighborhoods in which they were located. In general the evidence is overwhelming supportive of group home development, but each annotation and study must be examined individually if they are to be used effectively or if an advocate needs to counter citation of one of these studies by opponents of community development. The author will provide copies of each of the individual studies for the private use of interested individuals at a cost of $.10 a page.

TITLE: Creating community acceptance of handicapped people

AUTHOR: Nelson, R.

PUBLICATION INFORMATION: 1978

Charles Thomas
Springfield, IL

This book primarily focuses on the role of an agency "Community Education Director" as being instrumental in bringing about long term social change. Nelson writes from many years experiences as a community organizer and nine years as a community education director. The author's thesis is that if integration is to really happen someone has to undertake the difficult task of changing society's attitudes and prejudices by education. While this "PR" focus may at first seem to be of little concern to the service provider or the planner, even a cursory reading of this book soon makes it clear that everyone in the service system should be sensitive to the issues it raises.

Nelson's work is highly practical on two levels: 1) It outlines the basic principles of social change and community organizing and 2) delineates the use of these principles in a formal role in an agency. In her presentation, Nelson begins by defining the problem of prejudice towards disabled persons in terms of 10 major barriers to integration. She then sketches a plan of action to overcome these barriers. The specific components in this program of public education are discussed.

The major issues in services for disabled persons are briefly outlined. The final section provides a framework for using an agency, even with its needs for such things a fund raising, as a vehicle for community education and organizing. Particular emphasis, in this latter section, is given to avoiding the pitfalls of "pity" and "charity" which are so often associated with agencies' fund raising.

TITLE: New life in the neighborhood: How persons with retardation and other disabilities can help make a good community better

AUTHOR: Perske, R./Illustrated by Perske, M.

PUBLICATION INFORMATION: 1980

Abingdon Press
201 Eighth Avenue
P.O. Box 801
Nashville, TN 37202

COST: $7.95

Written by well-known author and leader in the field of developmental disabilities, Robert Perske, New Life in the Neighborhood presents a compelling case for the integration of people with developmental disabilities into typical neighborhoods and communities. The book provides a clear and straightforward explanation of normalization, debunks the myths surrounding people with mental retardation, explains why both typical and disabled people benefit from community integration, and addresses commonplace fears such as the impact of small community residences on property values. Sensitively and clearly written, this book is directed toward a popular audience, including civic leaders, prospective neighbors of the community residences, volunteers, and other nonprofessionals. This is a key source for anyone involved in developing integrated community living arrangements.

TITLE: Gaining community acceptance: A handbook for community residence planner

AUTHOR: Stickney, P.

PUBLICATION INFORMATION: 1980

Community Residence Information Service Program
Westchester Community Service Council
237 Mamaroneck Avenue
White Plains, NY 10605

COST: $5.00

This book gives the planner and service provider a valuable outline of many of the public relations issues surrounding the establishment of a community residence. Section one discusses methods for analyzing a community and for determining strategies which can be effective in gaining support and resolving conflicts. Section two is an examination of obstacles to the development of community residence and a review of various laws, regulations, and court decisions which have helped overcome these obstacles. The final section reviews the role of the media in gaining support and gives examples of news stories, editorials and other public information efforts.

PARENTS, CONSUMERS, AND ADVOCATES

Parents as activists and consumers speaking out for themselves and their fellows, especially those who are unable to speak for themselves, are two of the most dynamic forces at work today in the field of developmental disabilities. The materials presented here fall into four categories: 1) resources for parents; 2) materials for use by self-advocates; 3) a book which, in addition to providing information for establishing a self-advocacy group, can help educate parents and professionals who want to understand and foster this movement; and q) information concerning "advocacy" in general and the various forms of voluntary advocacy.

TITLE: Hope for the families: New directions for parents of persons with retardation or other disabilities

AUTHOR: Perske, R., & Perske, M.

PUBLICATION INFORMATION: 1981

Abingdon Press
201 Eighth Avenue, South
P.O. Box 801
Nashville, TN 37202

COST: $4.95

As the authors say, "this book is for families who are trying to turn a tough situation into a rich experience." This is one of THE books for families in which one of the members has a disability. In 28 brief up-beat chapters the author confronts and exorcises the ghosts which our culture imposes on disabled persons and their families. He shows many ways parents and families can overcome their fears and inhibitions. Some of the wide ranging topics discussed include: changing world views, theology, human dignity, sexual development, family systems, and opening opportunities for persons with retardation and other disabilities. To clarify his meaning, draw out his implications, and encourage discussion the author concludes most chapters with mini-"Home"-work assignments entitled "Consider these options." The marvelous illustrations re-double the impact of this impressive little book.

TITLE: Unraveling the special education maze: An action guide for parents

AUTHOR: Cutler, B. C.

PUBLICATION INFORMATION: 1981

Research Press
2612 North Mattis Avenue
Champaign, IL 61820

COST: $12.95

As its title suggests, "Unraveling the Special Education Maze" is a book about how parents can effectively work with and advocate in schools to improve the quality of programming for their children. Barbara Coyne Cutler, a parent, has long been an activist on behalf of children's rights. She brings a wealth of experience and examples to the text.

In addition though, and perhaps more important, this book speaks to the issue of parent attitudes in a manner few other works have come close to accomplishing. Cutler describes how parents feel when they approach schools. She gives us an accounting of "good" and "not so good" ways in which school personnel treat families. This is a book filled with humor, commitment, and lots of food for consciousness raising. This book will be particularly popular with parents and, I suspect, with administrators as well. It has a lot to teach us all.

TITLE: Beyond the family and the institution

AUTHOR: Pieper, B.

PUBLICATION INFORMATION: 1979

Spina Bifida Association of America
343 South Dearborn, 319
Chicago, IL 60604

COST: $1.00

This pamphlet is written from the perspective of a parent who has had a lot of experience dealing with the lack of responsiveness of the "service" system. It provides the reader with some valuable insights into the problems and issues surrounding residential services for persons with developmental disabilities. This should be a particularly useful resource for parents who are only just beginning to reflect on their child's future need for a place of residence outside of the the family home.

The introductory section recounts the trauma a parent undergoes as they attempt to get appropriate services from a bureaucracy which seems to be primarily focused on tearing the family apart. A particular point is made of highlighting the apparent unwillingness of this system to respond to the often very simple needs of individuals and their families. Twenty questions are provided to give the reader a framework for the evaluation and monitoring of residential services. Five common myths which often interfere with attempts to obtain services are debunked. Some of the problems, issues, funding sources, and models in residential services are also discussed. As a conclusion, 13 "futuristic" principles which should guide parent advocacy and should be goals for a realistic public policy towards disabled persons are outlined.

TITLE: Advocacy in residential programs

AUTHOR: Rude, C. D., & Aiken, P. A.

PUBLICATION INFORMATION: 1982

Research and Training Center in Mental Retardation
Texas Tech University
Box 4510
Lubbock, TX 79409

COST: $10.00

This book is intended as a training guide for advocates for people in residential programs. In this regard it presents information about the various types, aims, and procedures of residential programs, as well as about rights and program standards. This basic information is intended to be applicable to various types of advocacy; including self-advocacy, citizen advocacy, system advocacy, and legal advocacy. This resource also attempts to target and train advocates in the skills which are required by an effective advocate. These are specifically addressed in chapters which discuss model advocacy programs and different advocacy strategies.

TITLE: Citizen Advocacy: How to make it happen

AUTHOR: Research and Training Center in Mental Retardation

PUBLICATION INFORMATION: 1980

Research and Training Center in Mental Retardation
Texas Tech University
Box 4510
Lubbock, TX 79409

COST: $8.00

This text discusses the foundations of citizen advocacy and how to set up and administer a citizen advocacy program. It further discusses the function of such a program. The information is presented in three parts. Part 1 gives an overview of citizen advocacy and tells how to assess community support, find a sponsor, incorporate, form a board, seek funds, hire staff, and select an office site. Part 2 provides tips on essential management functions. Part 3 discusses the program functions that are most critical for advocacy such as recruiting volunteers, screening and matching advocates and proteges, training, and follow-up.

TITLE: The self-advocacy workbook

AUTHOR: Gardner, N. E. S.

PUBLICATION INFORMATION: 1980

Technical Assistance for Self-Advocacy Project
Kansas Center for Mental Retardation and Human
Development UAF
University of Kansas
Lawrence, KS 66045

This is a resource for disabled persons. It provides a framework for learning about self-advocacy, organizing a group, and undertaking group action to deal with issues of common concern. The materials are specifically geared for use by a group. Each chapter attempts to focus on only one discrete aspect of organizing. Also, the structure of each presentation is the same throughout in order to minimize any problems the group might have with the management of their meetings.

TITLE: Rights Now: A learning program on rights and responsibilities.

AUTHOR: Project Independence, Social Planning Services, Inc.

PUBLICATION INFORMATION:

National Institute on Mental Retardation
P.O. Box 5019
Downsview, Ontario, Canada M3M 3B9

COST: $250.00 plus postage & handling

This is a reading-free, self-instructional program for self advocacy. A Leaders Guide-on-tape describes the program, materials, and activities for the non-reader. An accompanying illustrated manual is color-coded to match the labels on the relevant tapes. A detailed written version of the leader's guide is also provided. A slide/tape presentation entitled "Our Place" uses vignettes, featuring the residents of a group home as they confront a wide range of situations, as a vehicle to teach the balancing of rights and responsibilities. A poster presentation is used to reinforce the problem solving strategy used throughout the materials. Group problem solving of six situations of people with "rights problems" is structured by large flip chart books (11" x 11") and color coded tape cassettes which present the problem and suggest what issues need to be discussed. This is an expensive package; but, it is well worth the investment for a service agency, secondary school, or adult education situation which serves developmentally disabled persons.

TITLE: Action through advocacy: A manual for training volunteers

AUTHOR: Research and Training Center in Mental Retardation

PUBLICATION INFORMATION: 1980

Research and Training Center in Mental Retardation
Texas Tech University
Box 4510
Lubbock, TX 79409

COST: $12.00

This manual is useful for training volunteers in state protection and advocacy agencies. It is set up as a curriculum to train volunteer advocates who have direct relationships with developmentally disabled people. The broad goal of the training is to give volunteer advocates knowledge of developmental disabilities and of the advocate's role, an understanding of the attitudes that affect the lives of developmentally disabled persons and basic skills in communication, assertiveness, and taking action for change.

Because advocacy programs are so varied in structure and in the ways they use volunteers, one main aim in this curriculum's design has been flexibility. To meet this need, this manual includes both instructions for trainers (on colored paper) and background materials and work sheets that the trainer can copy inexpensively for trainees (on white paper). This design allows a trainer to individualize the curriculum according to the needs and purposes of the advocacy program.

TITLE: We can speak for ourselves: Self-advocacy for mentally handicapped people

AUTHOR: Williams, P., & Shoultz, B.

PUBLICATION INFORMATION: 1984

Indiana University Press
Bloomington, IN

The fundamental right of speaking for oneself has long been denied to mentally handicapped people, who have usually had decisions made for them about every detail of their lives. They have, in other words, been taught dependence. In recent years, however, the Self-Advocacy Movement has been proving that people who can learn dependence can also learn independence. This book tells the story of People First of Oregon, Project 2 of Nebraska, and similar projects in England, where participants have been building the skills necessary to take charge of their own lives. The book offers practical advice and support for parents, human service workers, and others interested in developing self-advocacy for mentally handicapped people. It includes detailed models of existing projects, lists teaching materials, and presents personal accounts by mentally handicapped participants in self-advocacy projects both in the United States and in England. This book is also a valuable resource to sensitize the direct service worker, the administrator, and the public official to the importance of self-advocacy.

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